Social interactions among research stakeholders and ethical issues in the context of community engagement in Malawi

By

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Declaration

This thesis is the result of my own work. The work was carried out in accordance with the requirements of the University of Malawi, College of Medicine and University of Liverpool joint PhD programme. My contribution of the reported work are as follows:

Activity	**Responsibility**
Conceptualisation of protocol	Sole
Data collection and transcription	Shared
Data Management	Sole
Data Coding	Sole
Data analysis and interpretation of results	Sole
Thesis preparation	Sole

The material presented in this thesis has not been previously submitted elsewhere for the award of any degree. Each significant contribution in this thesis from the work of other people has been cited and referenced.

Deborah Nyirenda

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Abstract

Background

This thesis aims to examine community engagement practices and consequent effects on ethical research, knowledge re-production and study acceptability. Community engagement is promoted in international ethical guidelines for health research to engage communities in research design and implementation. Limited evidence exists on practical translation of these international ethical guidelines to improve ethical research particularly, in low resource settings. This study was undertaken to address this knowledge gap by using three ethnographic case studies from a low resource setting in Malawi.

Methods

A qualitative research design was used to understand community engagement practices in light of a theoretical framework of neo-colonial research relations. Three research projects were purposively selected as ethnographic case studies focusing on an urban, rural and hospital setting. Community engagement approaches employed by the studies included: community meetings, consultation Focus Group Discussions (FGDs) and involvement of research volunteers. I used participant observation to understand unarticulated aspects of community engagement. Field notes from participant observation were triangulated with 43 in-depth interviews and 17 FGDs with community leaders, research staff, community members and research participants. Field notes and transcripts from the interviews and FGDs were coded in Nvivo 10 QSR to identify main themes. Thematic analysis was used to analyse and interpret findings by applying theories of neo-colonial research relations.

Results

Although international ethical guidelines promoted active involvement of communities in research design, neither researchers nor community members wished to engage in fully collaborative partnerships. Community engagement processes were shaped by historical experiences with service providers, political context, power dynamics between research stakeholders as well as social norms of interacting with outsiders. In addition, the broader socio-economic context and local power structures raised issues of structural coercion. Rather than improving ethical research practice, community engagement often influenced research participation and did not yield mutual benefits. While the researchers aim of engagement reflected attitudes of imparting scientific information to improve informed participation, collectivist social norms led to knowledge re-production and collective power to participate or resist research. These findings challenge the assumption that associates increased research literacy alone with study participation.

Conclusions

This thesis identified gaps in community engagement approaches purportedly designed to strengthen collaborative partnerships and ethical research practice. Community engagement was used to legitimize the research agenda determined by powerful outsiders. Lack of community awareness of ethical guidelines or activism for collaborative partnerships affected successful translation of collaborative partnerships. Thus, democratic ideals promoted in collaborative partnerships did not replace deficit models of engagement because community engagement was still situated within a framework of neo-colonial relations between recipients of aid or research and those who provide it. These results raise important questions

on how community engagement in low resource settings ought to balance between bridging research stakeholders' contradictory expectations.

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Abbreviations/acronyms

ADC	Area Development Committee
ART	Antiretroviral Therapy
BTI	Bacillus Thuriengensis Israelensis
CAG	Community Advisory Groups
CAB	Community Advisory Boards
CADECOM	Catholic Development Commission in Malawi
CBO	Community Based Organisation
CBPR	Community Based Participatory Research
CDC	Centers for Diseases Control
CE	Community Engagement
CEBESA	Centre for Bioethics in Southern Africa
CERI	Community Engagement in Research Index
CHAM	Christian Health Association of Malawi
CIOMS	Council for International Organisations of Medical Sciences
COM	College of Medicine
COMREC	College of Medicine Research Ethics Committee
DFID	Department for International Development
DHO	District Health Office

DPP	Democratic Progressive Party
FGD	Focus Group Discussion
HI	House Improvement
HSA	Health Surveillance Assistants
IRB	Institutional Review Board
ITN	Insecticide Treated Nets
KEMRI	Kenya Medical Research Institute
LA	Lumefantrine Artemether
LSM	Larval Source Management
LSTM	Liverpool School of Tropical Medicine
MCP	Malawi Congress Party
MLW	Malawi Liverpool Wellcome Trust Clinical Research Programme
MMP	Majete Malaria Project
MP	Members of Parliament
MWR	Majete Wildlife Reserve
NGO	Non-Governmental Organisation
NHS	National Health Services
NICE	National Institute for Health and Care Excellence
NIH	National Institute of Health

PRA	Participatory Rural Appraisal
PCV	Pneumococcal Conjugate Vaccine
PCVPA	Pneumococcal Carriage in Vulnerable Populations in Africa
PEA	Primary Education Advisor
PI	Principle Investigator
PPI	Patient and Public Involvement
PTA	Parents Teacher Association
QECH	Queen Elizabeth Central Hospital
RBM	Roll Back Malaria
SMC	School Management Committee
SP	Sulfadoxine Pyrimethamine
SPITT	Studying the intrapulmonary pharmacology and immunology of Tuberculosis therapy
SSI	Semi structured interviews
TA	Traditional Authority
TB	Tuberculosis
UDF	United Democratic Front
USA	United States of America
USD	United States Dollar

VDC	Village Development Committees
VHC	Village Health Committees
WHO	World Health Organisation

Glossary of terms

DEM	The District Education office is headed by a District Education Manager
Health Animator	These are community volunteers residing in the geographical locations where research was taking place who were trained to facilitate malaria workshops and to assist with implementation of interventions
LSM	Refers to management of breeding sites for mosquitoes with an aim of reducing the population of mosquito larvae
PEA	A district is divided into zones and a Primary Education Advisor is head of each zone
PTA	This is an association of teachers and parents who act as trustees of the school
SMC	Is responsible for development activities and day to day running of the school

Local language terms

Achipatala	Refers to people who are trained as health care providers
Afiti	Witches
Amalungo	Refers to MMP study or staff and volunteers involved in the study
Azaumoyo	Refers to community based health care workers popularly known as Health Surveillance Assistants
Boma	Refers to the government or staff employed by the government
Chiuta	God
Chitukuko	Development
Dokotala	Doctor
Kafukufuku	Means research, however the term also has multiple interpretations
K*atemera*	Vaccination
Kutemera	Traditional medicine aimed to prevent one from illnesses and other misfortunes
Kupopa magazi	Drawing blood
Mabungwe	Institutions or organisations
Magazi	Blood
Maula	Rituals used to determine the causes of misfortunes
Mkesha	A tree shade where community meetings are normally conducted. The name *'mkesha'* is possibly a vernacular term for acacia tree

Mphini	Tattoo marks used to administer traditional medicine
Nkaningwiningwi	Mosquito larvae
Nyanga	Horn used to perform rituals that prevent misfortune
Ufiti	Witchcraft
Umunthu/Ubuntu	Showing kindness or mutual responsibility towards others
Zithumwa	Talisman used to prevent misfortune

Publications

Publications from part of the PhD data

Nyirenda D, Sariola S, Gooding K, Phiri M, Sambakunsi R, Moyo E, Bandawe C, Squire B, Desmond N. (2017) *'We are the eyes and ears of researchers and community members'* Understanding the role of Community Advisory Groups to represent researchers and communities in Malawi. *Developing World Bioethics Journal*. 00:1-9. https://doi.org/10.1111/dewb.12163

McCallum A*, **Nyirenda D*,** Lora W, Khoo S, Sloan D, Mwandumba H, Desmond N, Davies G. (2016) Perceptions of Research Bronchoscopy in Malawian Adults with Pulmonary Tuberculosis: A Cross-sectional Study. *PLos ONE.* 11(4):p.1-12. https://doi.org/10.1371/journal.pone.0165734

Other relevant publications during the PhD period

Nyirenda D, Gooding K, Lora W, Kumwenda M, McMorrow M, Everett D, Desmond N. (2018) Complexities and dilemmas in community consultation on the design of a research project logo in Malawi: A qualitative study. *PLoS ONE* (Accepted for publication with minor revisions)

Gooding K, Makwinja R, **Nyirenda D**, Vincent R, Sambakunsi R. (2018) Using theories of change to design monitoring and evaluation of community engagement in research: experiences from a research institute in Malawi [version 1; referees: 3 approved]. *Wellcome Open Res* 2018, **3**:8 (doi: 10.12688/wellcomeopenres.13790.1)

Nyirenda D, Makawa T, Chapita G, Mdala C, Nkolokosa M, O'byrne T, Desmond N, Heyderman, R. (2016) Public engagement in Malawi through a health-talk radio programme '*Umoyo nkukambirana*': A mixed methods evaluation. *Public Understanding of Science.* 22(2): p.229. https://doi.org/10.1177/0963662516656110

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Chapter 1: Introduction

1.0 Introduction

Community engagement emerged with the rise of global health programmes to address health inequities due to diseases such as HIV/AIDS, lower respiratory infections, malaria and Tuberculosis. Research for these diseases in low resource settings is however considered inadequate due to limited funding from local government and shortages of human resources (Nachega et al., 2012). As a result, most of the global health research programmes are initiated and led by researchers from the global north in order to strengthen research capacity and they rely on active participation of community members from low resource settings (Reynolds and Sariola, 2018). The extent to which global health programmes can be implemented in the context of structural inequalities and neo-colonialist research relationships between high and low resource countries however remains questionable (Boshoff, 2009, Godoy-Ruiz et al., 2016). As such, collaborative partnerships between researchers, policy makers and communities in developing countries are promoted to minimize the possibility of exploitation and ensure that research is responsive to community needs (Emanuel et al., 2004). Some funders have therefore made community engagement in global health research mandatory to resolve power differences between researchers and to allow marginalised voices to be represented in the production of scientific knowledge.

The term ‘community engagement’ however entails a wide range of interactions between researchers and communities to inform, consult or actively engage communities in decisions around research. Despite international recommendations to incorporate communities' perspectives on the value and risks of proposed research, existing literature shows that community engagement continues to be the focus of unresolved debates concerning roles of community members in research. Firstly, power differentials between researchers and

communities due to unequal access to resources and education present challenges to lay community members to understand research objectives or negotiate decisions with researchers (Parry Sarah., 2012, Tindana., 2011). Secondly, technical expertise required in health research makes the question of who may legitimately represent a community in research difficult (MacQueen et al., 2001, South and Phillips, 2014). Additionally, there are concerns that researchers and communities often have competing agendas (Anderson et al., 2012, Mikesell et al., 2013, MacQueen et al., 2001) and that incorporating lay perspectives in research design may compromise quality of research. For instance a literature review on community engagement reported that tailoring interventions to suit community needs affected quality of randomised control trials by contaminating control groups (Cyril et al., 2015). Previous studies have also reported challenges to evaluate community engagement due to variations in meanings and practices (Bauer et al., 2007, Tindana., 2011, Nyirenda et al., 2016, South and Phillips, 2014) leading to gaps in the literature on outcomes of community engagement in improving ethical research.

Building on Geissler's (2011 p.20) notion that, 'colonial public health was a dimension of colonial hegemony and social control, where science served to legitimize cultural superiority', this study seeks to analyse community engagement implemented in global health research projects in light of a theoretical framework of neo-colonial relations. A qualitative research design was used to gain in-depth understanding of community engagement as experienced by various research stakeholders in three medical research projects: Pneumococcal Carriage in Vulnerable Populations in Africa (PCVPA), Majete Malaria Project (MMP), Studying the Intrapulmonary Pharmacology and Immunology of Tuberculosis therapy (SPITT). Community engagement activities in PCVPA focused on meetings with senior education officials, parents' teacher association committees, parents and students. In MMP study, community engagement activities focused on selection of research

volunteers and committee members to assist in educating other community members to implement community based interventions. Finally, in SPITT study, focus group discussions (FGD) were conducted prior to study implementation to explore TB patients and community members' understanding of study information on bronchoscopy based research and to seek their feedback on the research. Feedback from the FGD was then used to inform the development of study information sheets and consent forms. My thesis examines factors shaping social interactions among research stakeholders and consequent effects on community engagement practices, ethical research and study acceptability.

1.1 Research objectives

My main aims for this research were twofold 1) to understand the purpose, relevance and benefits of community engagement among research stakeholders in medical research and 2) to use this understanding to inform community engagement practices at Malawi Liverpool Wellcome Trust (MLW) and other research institutions in low resource contexts. I initially formulated five objectives which slightly changed over the course of the research to understand emerging themes from the data. The specific objectives were to:

I. Analyse how different communities are engaged in the conduct of medical research.
II. Explore social interactions among research stakeholders and consequent effects on community engagement practices.
III. Understand the rationale and expectations from community engagement among research staff and communities.
IV. Explore how knowledge is reproduced through the interaction of researchers and community members

V. Assess the benefits and risks of community engagement to ethical research practice.

1.2 Definition of key terms

The term community engagement is broadly defined across different settings as a means of imparting information, consultation or collaborative partnerships between researchers and communities in research design and implementation (Ahmed and Palermo, 2010, Carson, 2008, NICE., No date). Likewise, the term 'community' has multiple interpretations and can be used to describe a group of people residing within a particular geographical location; a group of people with common identities, interests or characteristics; or a group of people being served by one public health facility (Marsh et al., 2011, MacQueen et al., 2001). Given the ambiguities of the terms 'community' and 'community engagement', community engagement practices vary across contexts, research designs and research topics. Additionally, the terms community/public engagement, community/public involvement, community/public participation, community/public consultation, community/public collaboration are often used interchangeably in the literature.

In this research, the working definition of community engagement has been adopted from the Council for International Organisations of Medical Sciences (CIOMs) because it offers direct guidance on how to strengthen representation of communities in study design and to minimize harm to participating research communities. Throughout this thesis, community engagement will be defined as '*a process of engaging potential participants and communities in a meaningful participatory process that involves them in an early and sustained manner in the design, development, implementation, design of the informed consent process, monitoring of research and in the dissemination of its results'* (Council for International Organisations of Medical Sciences., 2016). In addition, the definition of a community will be slightly modified

from Macqueen's (2001) definition to include either a group of people with common characteristics who may not reside in a specific location, or a group of people with diverse or common characteristics but residing in a specific location. A community will therefore be defined as a group of people who are either linked by a particular disease or a group of people residing in a specific geographical setting.

1.3 Argument of the thesis

Drawing on the literature on medical research in Africa, I used theories of neo-colonialism or academic imperialism to interpret my study results on factors shaping community engagement as well as outcomes on ethical research and study acceptability. According to Nkrumah, "*the essence of neo-colonialism is that the state which is subject to it is, in theory, independent and has all the outward trappings of international sovereignty. In reality its economic system and thus its political policy is directed from outside*"" (Nkrumah, 1966). Thus, neo-colonialism manifests itself through foreign aid programs or technical advice where powerful outsiders control decisions on political, economic and social issues (Wickens and Sandlin, 2007). The powerful outsider exercising control may either be a country which previously colonized the territory or privileged elites.

I used theories of neo-colonialism rather than postcolonialism to show how neo-colonial practices are sustained in the context of community engagement. According to Ndlovu-Gatsheni (2013), the intended postcolonial dispensation was replaced by a coexistence of 'postcolonial neocolonised' world where colonial powers use global snares to silence and dominate the non-western world. Thus, neo-colonialism does not imply that the colonial era is over as suggested in the term 'postcolonialism', it rather focuses on new forms of control and power retained by colonizing powers and privileged elites (Huggan, 1997). Theories of

neo-colonialism were therefore more relevant to understand how neo-colonial research relations undermine the ideals of participatory governance in global health research. My interpretation of results is therefore based on how colonial legacies and science as a discipline shape power relations among research stakeholders in the context of community engagement.

Sharma (2005) argued that the field of tropical medicine as well as global health is determined by neo-colonial policies that perpetuate colonizing practices by driving the research agenda, influencing the research questions and methods that are deemed legitimate, valuable or fundable. Implicit in global health knowledge production are ideas of western science being 'rational' and local knowledge or non-scientific perspectives as being 'irrational or primitive' and in need of correction with scientific information (Gaventa, 2001). Neo-colonialism is also referred to as academic imperialism "*when dependency relations (between countries) extend to universities and research activities...and researchers from rich countries have more funds at their disposal...more sophisticated apparatus of preparation, which enables them to dictate the research agenda, the research methods, and where to disseminate the research findings*" (Cathy, 1993 P. 70). Throughout this thesis, I will use the term neo-colonialism to refer to academic imperialism in the context of community engagement.

Since the field of global health is seen to perpetuate neocolonial practices and western ideologies that influence knowledge production in research (Sharma, 2015), some have proposed to decolonize the research agenda by privileging the voice of local people who have been historically excluded from knowledge production. Thus*, 'decolonizing research methods'* emerged as a way of challenging positivist frameworks that define what is deemed as scientific and which privileges the voice of research experts (Bermúdez et al., 2016). Decolonizing research methods are seen to raise social consciousness, empower groups who

have been historically colonized and promote mutual benefits of research (Bermúdez et al., 2016). Similarly, community engagement in research is one of the means considered in principle to decolonize the research agenda and empower communities to contribute in research design and implementation.

In order to understand how power relations among research stakeholders shape community engagement, I draw from Michel Foucault and John Gaventa's analysis of power. Community engagement or public engagement is one of the means to overcome power inequalities in the conduct of research by shifting from deficit models of improving research literacy to more participatory and democratic approaches (Davies, 2011). Foucault however argued that 'knowledge is power' and that there is a connection between the two (Gaventa, 2001) in that power may produce knowledge or sustain inequalities. Consequently, those who produce knowledge also have the power to present it as valid and to subject others to that knowledge. Thus, despite increasing participation in knowledge production, scientific methods or rules can be used to allow some voices to be heard while discrediting others.

In addition, I also used John Gaventa's analysis of the spaces, places and forms of power to examine power relations among research stakeholders. According to Gaventa, 'spaces' are seen as the opportunities and channels where citizens can act to potentially affect decisions and relationships that affect their lives and interests (Gaventa, 2006). Continuum of spaces may include: closed spaces where decision making spaces are limited to powerful actors, invited spaces where people are invited to participate by powerful actors and claimed/created spaces demanded by less powerful actors. In this case, I will examine the spaces for community participation by asking how they were created, with whose interests and terms of engagement. A second way of analysing power relations is to focus on places and levels of participation between the local, national and global arenas (Gaventa, 2006). By focusing on the levels and places for participation, I aim to explore how interrelationships between

international ethical guidelines, national regulations and local power structures shape community engagement in global health research. Thirdly, I will focus on how dynamics of power shape the inclusiveness of participation by looking at three forms of power namely: visible power, hidden power and invisible power (Veneklasen, 2002). Visible power refers to the formal rules, authorities, institutions, and procedures of decision making. Hidden power refers to how powerful actors maintain their influence by controlling the agenda and decision making. Finally, invisible power shapes the psychological and ideological boundaries of participation as well as people's perceptions of their superiority and inferiority. By examining how these different forms of power manifest as research stakeholders interact, I will show how neo-colonial research relations shape community engagement.

A majority of publications from Africa have reported ethical challenges in relation to power relations between researchers, community leaders and field workers (Angwenyi et al., 2013, Chantler et al., 2013, Molyneux et al., 2010). Few empirical studies have analysed relationships of power in global health research in the context of academic imperialism. This study seeks to contribute to these knowledge gaps by using an ethnographic case study approach focusing on three research projects in urban, rural and hospital settings in Malawi. Therefore, this study makes a major contribution to the literature on community engagement by demonstrating how powerful outsiders and local elites follow neocolonial patterns of driving the research agenda, determining the terms of engagement with communities, and standards for ethical research practice. In addition, I also show how collectivist social norms lead to knowledge re-production in communities and collective power to resist research, thereby challenging assumptions that research literacy alone leads to study participation.

1.4 Structure of the thesis

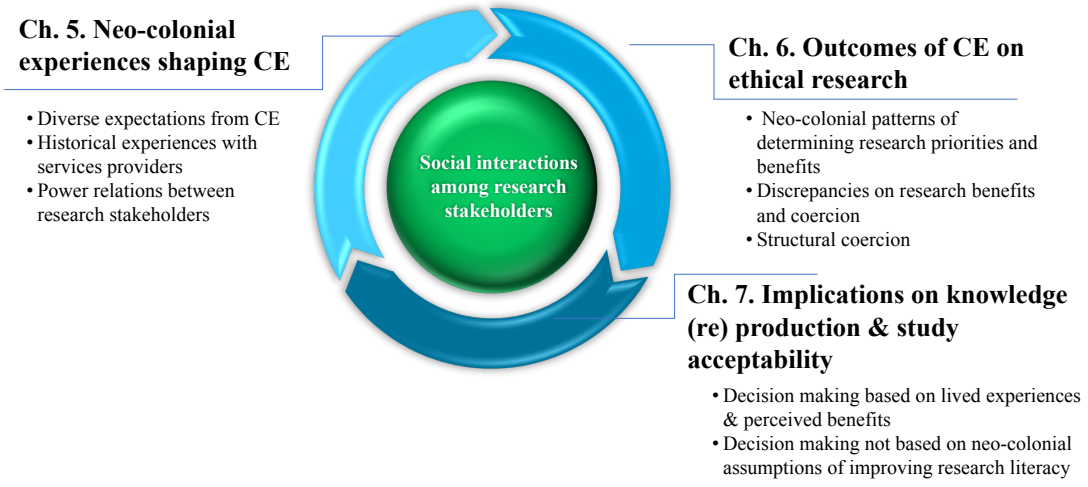
This thesis provides empirical data in response to the research objectives and is divided into eight chapters. In Chapter 2, I present the literature on models of health followed by bio-

power and medicine. Thereafter, I situate my research within the body of literature on community engagement. I present an overview of the meanings of community engagement, history of participatory public engagement or community engagement in research, frameworks used to guide community participation or community engagement and dilemmas reported in the literature on community engagement.

In Chapter 3, I present the historical, political and socio-economic context in Malawi where this research was conducted. I present an overview of health services and health research in Malawi. Thereafter, I present detailed information about the study settings and the three ethnographic case studies.

In chapter 4, I present the research design and methodology. I describe the rationale for using a qualitative research design and ethnographic case studies, how I selected the ethnographic case studies, and I provide detailed descriptions of the data collection approaches, data analysis, ethical dilemmas experienced, and study limitations.

Figure 1.1: An overview of main themes in the results chapters



The empirical findings are presented in chapters 5, 6 and 7 and Figure 1.1 gives an overview of the main themes in each chapter. In chapter 5, I discuss social interactions between research stakeholders and consequent effects on community engagement practices. I present an overview of all the community engagement activities in each case study, research stakeholders involved and the contradictory expectations of researchers and communities from engagement processes. After that, I present contextual factors that influenced community engagement processes pertaining to historical, political as well as social factors.

In chapter 6, I use ethical guidelines from CIOMs on community engagement and collaborative partnerships to demonstrate ethical questions arising from community engagement practices. I therefore discuss local structures aimed to promote ethical conduct of research, researchers and community members diverse perceptions of research benefits, and how the broader socio-economic context presents structural coercion to research participants.

In chapter 7, I discuss the outcomes of community engagement on knowledge reproduction in the communities and study acceptability or resistance. I present pre-existing communication approaches and how the community engagement approaches align with these. Thereafter, I show that decisions to participate in research were informed by historical experiences, perceived benefits of research and an interpretation of certain research procedures alongside local beliefs.

Finally, in chapter 8, I discuss my empirical findings in relation to the literature on community engagement, collaborative partnerships, neo-colonial theory, ethical research and knowledge production. Thereafter, I state my recommendations and conclusions drawn from the study.

Chapter 2: Literature review

2.0 Introduction

This chapter reviews published literature on models of health, bio-power and medicine, community engagement in global health research, community participation, public engagement, medical research in Africa, as well as research ethics. I conducted a literature search in the University of Liverpool-Discover database using the following keywords: community engagement, public engagement, community participation, and research ethics. An initial literature search of 'community engagement and research' and 'public engagement and research' generated 55, 587 and 50, 493 articles respectively and this excluded non-English articles. As such, I could not conduct an exhaustive literature review due to practical constraints. In order to identify relevant publications to include in this literature review, I decided to narrow my focus on reviews, empirical papers and commentaries that focus on 'community engagement and health research'; 'community engagement and global research'. This search therefore excluded publications on science communication, community mobilization or communication approaches that were not defined by the authors as 'community engagement'. Having reviewed the relevant literature on community engagement, I also searched for literature on approaches that were used to engage communities in research such as Public and Patients Involvement (PPI), Community Advisory Boards (CABs), Community Based Participatory Research (CBPR), and other community consultation activities. In addition, I identified literature on models of health, bio-power, collaborative partnerships, participatory development, knowledge co-production, history of medical research, neo-colonialism and community representation following recommendations from others.

Although the value of community engagement is increasingly being recognized, global health institutions, and authors employ different definitions of community engagement in research (See Appendix 1). In order to illustrate the complexities in how community engagement is understood and employed, I reviewed definitions of community engagement used by various authors and global health institutions in appendix one. A review of the definitions of community engagement covered in this review demonstrated that common themes of engaging communities included establishing partnerships or collaboration with communities (Ahmed and Palermo, 2010, Carson, 2008) and inclusive participation of communities in decision making to improve their health (WA Health., 2007, National Co-ordinating Centre for Public Engagement, 2010).

The diversity in terms of how community engagement is understood is also reflected in the variety of engagement goals across different settings, institutions, study sites or study designs. Previous studies have reported diverse goals of engaging communities to serve both instrumental and intrinsic purposes such as to: facilitate communication, solicit community feedback, facilitate implementation of research, improve community understanding of research, improve informed consent and to actively engage communities in research design (Marsh et al., 2008a, Vallely et al., 2007, Nyika et al., 2010). Much of the literature on community engagement has also focused on providing guidance on how to ensure ethical research (Anderson et al., 2012, Ross et al., 2010b, Ross et al., 2010a, Mikesell et al., 2013, Emanuel et al., 2004, Pratt and Loff, 2014), establish trustworthy relationships with research communities (Anderson and Solomon, 2013, Yarborough et al., 2013, Quinn et al., 2013), roles of field workers (Molyneux et al., 2010, Angwenyi et al., 2013, Chantler et al., 2013), and experiences of various community engagement practices in different settings (Tindana., 2011, Marsh et al., 2008b, Okello et al., 2013, Angwenyi et al., 2014, Diallo et al., 2005, Marsh et al., 2010, Vallely et al., 2007).

I have presented this literature based on themes that I identified to provide a holistic account of the published work on community engagement and to highlight my contribution to the field of community engagement. I begin with a brief introduction of models of health, bio-power and medicine in section 2.1. Thereafter, I discuss the history of participatory public engagement in western settings in section 2.2. Having done this, I present literature on participatory processes of involving publics or communities in health services or research in order to situate community engagement within the broader literature on participatory processes. I therefore present literature on historical developments in participatory development in section 2.3. In section 2.4, I discuss approaches used to engage communities, and finally, challenges to evaluate community engagement. In the next section, I will present historical developments in relation to participatory public engagement in western contexts.

2.1 Models of health and power relations in the conduct of medical research

The increasing emphasis on community engagement in global health research calls for an understanding of how different models of health are considered in community engagement. As previously indicated in chapter one, community engagement is promoted in global health research to empower communities to be represented in the production of scientific knowledge. This emphasis on community engagement in international ethical guidelines therefore suggests a shift from extractive research to more participatory and collaborative processes of empowering community voices to be considered in the conduct of global health research. In this section, I aim to discuss various models of health and theories of power in relation to bio-medicine.

2.1.1 Models of health

The ultimate aim of strengthening community engagement in medical research is to improve health. According to the World Health Organisation (WHO), health is defined as the 'complete state of physical, social and emotional wellbeing and not merely the absence of

disease or infirmity'. There are however different models of health (Turshen, 1989). For instance, health and diseases can be explained by focusing on the physical or biological aspects of illnesses, or by understanding wider social factors that may influence health. These two approaches are called: bio-medical or clinical medicine; and social or public health models of health respectively (U205 Course Team., 1985). While the bio-medical approach focuses on diagnosis, cure and treatment of individuals and is often practiced by doctors or health professionals, the social model of health focuses on addressing the social determinants of health to prevent diseases. Distinctions between the bio-medical and social models of health are however blurred due to the assimilation of public health into clinical medicine. In addition, health may be understood by blending elements from bio-medicine and indigenous or religious beliefs and this is called medical syncretism (Muela et al., 2002). An understanding of these models of health is necessary to analyse how community engagement synchronizes multiple perspectives of health in global health research. In the next section, I present a brief history of clinical medicine and illustrate its bio-power.

2.1.2 Bio-power and medicine

Bio-medicine became professionalised in the 18th century in the global north. The introduction of academic credentials as well as formalisation of medical specialization closed the profession to outsiders and elevated the prestige of biomedicine (Neill, 2012). To date, the expertise of bio-medical professionals is widely recognized as powerful to address global health challenges. Thus, bio-medicine is seen to exercise bio-power by employing mechanisms to manage populations and discipline individuals. According to Gastaldo (1987), bio-power refers to the '*use of mechanisms of control and coercion for the productivity and health of human bodies and populations based on a view of them as resources or manageable objects'*. Bio-power is exercised through a set of two techniques called: bio-politics of the population and anatomo-politics of the human body (Gastaldo, 1997). Bio-politics employs

regulatory controls and interventions to manage population health while anatomo-politics focuses on individual bodies. For instance, medical professionals use health education to persuade people to make the 'ideal choices' to lead healthy lifestyles. Similarly, medical professionals are entitled by their scientific power to examine, interview and prescribe health options to patients. Bio-medicine therefore exercises bio-power by providing information, interventions or promoting behaviours that may interfere with an individual's choice. This shows that bio-medicine is by nature authoritative, patronising and undemocratic because it prescribes 'norms' and imposes truth about health to others.

Since the field of medicine involves an exercise of bio-power, this raises the question of how community engagement can help to democratise the conduct of medical research or resolve power inequalities between medical researchers and lay communities. Community engagement demands a shift from top-down scientific inquiries to bottom-up processes aimed at empowering communities to be involved in research design and implementation. The field of bio-medicine is however critiqued as potentially sustaining power inequalities by undermining lay people's autonomy and allowing bio-medical practitioners to dictate how lay people should deal with their own health care (Neill, 2012). For instance, lack of medical knowledge place lay people in vulnerable positions by constraining their autonomy to challenge decisions made by bio-medical practitioners (Lupton, 1997). In addition, age, ethnicity, and gender of the patient and doctor may also shape social interactions between medical professions and lay people in complex ways (Lupton, 1997). This exercise of bio-power may generate multiple outcomes such as compliance or resistance to engage with medical strategies through direct rejection of proposed strategies, non-corporation, silence, escapade, avoidance and concealment. A review of the history of community engagement is therefore necessary to understand the rationale of community engagement in global health

research. In the following section, I present the history of community engagement in global health research.

2.2 History of community engagement in global health research and scientific developments

The existing literature on public/community engagement indicates that the goals of engagement differ across settings with different historical, cultural and socio-economic contexts. While the literature on public engagement in western settings shows that public engagement was promoted to enhance co-production of knowledge and address mistrust due to failed scientific projects (Bauer et al., 2007), the history of medical research in Africa shows that community engagement was promoted to improve community understanding of research and to address mistrust due to history of colonialism, exploitation and misunderstandings of research (Graboyes, 2014a). Given the diversity in the meanings of engagement and goals of engaging communities, a description of the history of community engagement is necessary to understand the factors that have led to increased support for community engagement in global health research. In this section, I aim to present developments in the field of public engagement in western settings. I later on present the history of medical research in Africa with an aim of illustrating factors that have led to increased support for community engagement in these settings. By reviewing literature from these settings with diverse histories, socio-economic factors and literacy levels, I expect to highlight contextual factors that have shaped community engagement practices in these settings.

2.2.1 Public engagement in western settings

Public engagement activities in western settings have evolved from information sharing activities to more participatory processes. According to Bauer (2007), efforts to engage the public began in the United States of America (USA) and Europe around the 1960's with an

aim of improving 'scientific literacy' by educating the public about science. The need to improve scientific literacy arose following survey results from the University of Michigan, Survey Research Center which reported that only a minority of the public were interested in scientific issues and that knowledge of scientific issues was low (Miller, 1983). The main reason for promoting scientific literacy was to *'promote intelligent and informed participation'* in science policy issues and to improve the quality of science and technology (Miller, 1983). Despite having an aim to promote 'informed participation', emphasis was to improve understanding of scientific concepts in formal education. Scientific literacy was therefore measured by assessing knowledge of scientific issues and attitudes towards science.

During the 'scientific literacy' era, a number of surveys were conducted in USA and Europe to measure 'Public Understanding of Science' and attitudes towards science and scientists. In 1971 and 1981, surveys were conducted in USA to understand the proportion of the population that was interested or knowledgeable about science policy and to examine their attitudes (Miller, 1983). The results indicated that a small percentage of the public (20%) followed scientific matters regularly and demonstrated favorable attitudes towards science (Miller, 1983). In addition, surveys by the Commission of the European Communities in 1977 and 1979 reported favorable attitudes towards science amid anxieties about potential risks (The Royal Society., 1985). New concerns therefore emerged in the second half of the 1980s that the public may become unenthusiastic about science. In 1982, the Royal Society committee on science education in the United Kingdom (UK) therefore recommended that the council of the Royal Society should set up a committee to investigate ways of improving public understanding of science (Bodmer, 2010).

Following this, the Royal Society report published the 'Public Understanding of Science' report in 1985 which recommended improving the quality of science education and communication of science through mass media, children's activities, public lectures,

museums and libraries (The Royal Society., 1985).The main thrust in the report was that an understanding of science would promote national prosperity and raise the quality of decision making. Despite efforts to improve knowledge and attitudes towards science, Bauer (2007) reported that research findings from large scale surveys and other qualitative studies still reported negative attitudes towards science and scientists. This was triggered by the Bovine Spongiform Encephalopathy crisis which affected many people in UK and other failed scientific projects (Caplan, 2000). This experience led to the declaration of a '*crisis of trust'* or *'crisis of public confidence'* (Bauer et al., 2007). Another report was therefore published in 2000 by the House of Lords entitled 'Science and Technology' to offer alternative ways of engaging the public in research (House of Lords, 2000).

The previous models of public engagement (Scientific literacy and public understanding of science) were critiqued as 'deficit models' because of the assumption that the public was ignorant about science and they needed to be educated or informed (Bauer et al., 2007). The Science and Technology report published in 2000 promoted another way of engaging the public in two-way dialogue to earn public trust. Some of the recommendations from the report were to improve dialogue and rebuild trust between scientists and publics in the early stages of scientific projects through deliberative polling, focus groups, internet dialogues and others. The report also recommended that Higher Education Funding Councils should support and award researchers who share their results with the public. The common practice previously was that researchers should present their results in scientific journals and not to the general public where the research was conducted.

Apart from the scientists' or researchers' recognition of the need to rebuild trust with publics by involving them in research design, some communities also advocated for public participation in research design. Community activism in North America and Europe therefore created an opportunity for collaboration between health researchers and lay communities

(International AIDS Vaccine Initiative., 2012). While participating research communities were traditionally viewed as research subjects or potential users of the outcomes (Slevin et al., No date), this began to change in 1970 when women's health advocates protested about inadequate inclusion in biomedical research. They demanded a role in decision making regarding research on contraceptives and other women's health issues (International AIDS Vaccine Initiative., 2012, Slevin et al., No date). In the 1980s, AIDS activists and communities affected by HIV/AIDS in North America and Europe also demanded to be involved in biomedical research because inclusion and transparency were considered as ethical responsibilities (Slevin et al., No date). In response to their demands, involvement of CABs to advise on protocol development became a requirement by US and European donors and consequently '*exported to international sites through donor requirements'* (Slevin et al., No date). The number of CABs in medical research conducted in Asia and Africa therefore expanded due to donor requirements, despite the differences in terms of education and research literacy between communities in western settings and in developing settings.

Numerous challenges were however observed when translating an 'activist led' CAB strategy to a 'researcher led' CAB in developing countries where untrained and marginalised individuals were pulled into relationships with western educated researchers (Slevin et al., No date). Challenges included: lack of clarity on the roles of CAB, lack of power to influence the research agenda, and challenges to balance between being accountable to researchers and communities. Nevertheless, community engagement is promoted in global health research to improve ethical research, increase transparency and accountability of research, and finally strengthen local capacity and infrastructure (Slevin et al., No date). Ethical guidance to engage communities in the conduct of medical research were therefore included in CIOMs guidelines in 2016 (Council for International Organisations of Medical Sciences., 2016).

The history of public/community engagement in western settings shows that participatory community engagement was advocated due to failed scientific projects and community activism. Thus, participatory approaches developed in western settings were introduced in other settings without adequately taking into account the local needs and context such as colonial legacies. In the next section, I present the history of colonialism and medical research in Africa.

2.2.2 Colonialism and medical research in Africa

The introduction of bio-medicine and medical research in Africa appears to be intertwined with experiences of colonial conquest. The idea that western countries were advanced in terms of science and technology was seen to justify colonial conquest (Hokkanen, 2012). Tropical diseases such as sleeping sickness, measles and plague however posed as a threat to the economic viabilities of colonies because they affected the labour force. While early colonial medical services focused on the health of Europeans only (Beck, 1972, Hokkanen, 2015), it was later noted that the health of colonial subjects needed to be improved in order to raise their earning power (Hokkanen, 2015). Early colonial medical research and campaigns were therefore introduced to prevent the spread of diseases (Vaughan, 2013).

Even though medical research was recognized as essential to address emerging epidemics, the conduct of research was less systematic during the colonial years. Firstly, methods for designing or analyzing trials were less developed and there were no ethical standards to protect research subjects from exploitation (Tilley, 2014). Medical researchers therefore had to deceive, coerce, manipulate and even threaten to conduct research or prevent the spread of diseases. In order to encourage participation, the colonial administration issued criminal laws that prohibited indigenous healing practices while imposing compulsory bio-medical practices such as vaccination (Hokkanen, 2015). Some of the chiefs also issued fines, physical beatings or threatened to banish people from their villages if they refused to

participate in research or comply to bio-medical procedures (Graboyes, 2010). The involvement of chiefs or the colonial administration however compromised individual autonomy to consent and led to resentment towards research (Graboyes, 2010). In Malawi for instance, smallpox police and chiefs were engaged to tour villages and enforce vaccination (Vaughan, 2013). The smallpox policemen however had challenges to persuade people to receive vaccination because the vaccination was painful such that people could not work afterwards. In addition, the vaccines were inert by the time they administered to people and proved unsuccessful to prevent smallpox. So, despite efforts to prevent people from smallpox, a severe strain claimed many lives and small pox remained a serious public health problem until the 1960's (Vaughan, 2013). Local people therefore formed their own negative and positive opinions of bio-medicine and continued to use indigenous medicine. To date, medical syncretism has remained the norm in most African settings.

Due to experiences of community resistance towards medical research, Graboyes (2010) reported that some researchers in East Africa opted to explain partial information about research while concealing issues of blood sampling in order to get community approval and to prevent conflicts (Graboyes, 2010). Similarly, others misrepresented the research objectives, outcomes and risks in order to ensure participation (Graboyes, 2014a). For instance, a researcher in Tanganyika asked the chief to tell residents to go and receive free inoculation and yet the researcher intended to collect blood samples from children (Graboyes, 2014a). This lack of transparency soured social relations between researchers and communities and consequently fueled stories of lying and blood stealing in many African settings. In other cases, medical researchers worked in health facilities as medical doctors which consequently led to expectations of treatment after giving out blood samples (Graboyes, 2010). Since research was conducted in settings with high prevalence of diseases and low coverage of treatment in order to demonstrate effects, some people participated in

research in order to access treatment (Fairhead et al., 2006, Graboyes, 2014a, Whyte, 2011). Lack of transparent communication led to mistrust between researchers and participating research communities.

In addition, colonial efforts to create export economies also had adverse effects on health of Africans. As demand for industrial laborers increased, this led to massive migration of men to expanding urban centres. For instance, Vaughan (2013) reported that movement of men as labour migrants begun in the colonial period because the government relied on colonial subjects to carry goods, build infrastructures or work in mines. Men who migrated from East Africa to Southern Africa therefore brought back diseases of industrialisation such as TB and syphilis. In the mining regions of Southern Africa and Belgian Congo for instance, the prevalence of TB was high and migration facilitated the spread of diseases (Beck, 1972). This social disruption of the colonial period was therefore seen as bringing new diseases that did not have indigenous means of control.

More generally, even though bio-medical research was introduced with modernity's promise of progress and wellbeing, this did not always materialise and sometimes led to undesirable outcomes. Uncertainties around research outcomes and failure to eradicate health problems also affected local people's trust in bio-medical research. In Congo, Uganda, Sudan and Tanzania, for instance, efforts to create large scale Agriculture plantations made people more vulnerable to vector borne diseases due to the altered environment. Many people therefore died from *African Trypanosomiasis* because the tsetse fly habitats had been transformed by bringing tsetse flies in closer proximity with humans and distancing them from animals (Tilley, 2014). Despite efforts by the colonial government to eradicate the disease through lumbar punctures and treatment drugs, these bio-medical procedures proved to be painful and treatment drugs led to blindness, brain damage and even death. Consequently, invasive procedures involving lumbar punctures and failure to address post experiment adverse effects

in Africa fueled mistrust in bio-medical research (Neill, 2009, Tilley, 2014). Death of people in the settings where research was conducted also strengthened the credibility of bad rumours around research (Graboyes, 2010).

Despite the historical, political and geographical differences across African countries, concerns around blood stealing, trade in body parts, surreptitious birth control and deliberate spreading of diseases have been widely reported (Geissler and Pool, 2006, Fairhead et al., 2006, Graboyes, 2010). Even though these stories were dismissed by researchers as rumours based on superstition and ignorance, they led to negative views of research which affected future recruitment of study participants or adoption of health interventions. Geissler and Pool (2006) have also argued that rumours are a symptom of poor relationships and unequal distribution of research benefit, where researchers are seen to increase their wealth by selling blood and body parts while eradicating the African population with diseases such as AIDS (Geissler and Pool, 2006). Thus, '*a century of medical research organized by the Germans, British, International organizations and now East Africans has shaped local opinion of the bio-medical system'* (Graboyes, 2014b p.398).

To date, funding for research on global health appears to follow colonial relations, where donors from the global north give to countries that were previously colonised (Gardner and Lewis, 1996, Boshoff, 2009). Global health research programmes also continue to increase for both economical and research capacity building reasons to address global health challenges (Boshoff, 2009). For instance, the cost of conducting a clinical trial in India is far cheaper than the cost of conducting a similar trial in USA due to savings in staff costs and research participant recruitment costs (Lang and Siribaddana, 2012). The increasing number of global health research programmes in the global south is therefore perceived as presenting a risk of creating a 'a 21st century scramble for Africa' by countries from the global north (Crane, 2011). Thus, the field of global health is critiqued as a means of perpetuating neo-

colonial ties where researchers from the global north dominate in the conduct of global health research and publications to brand their institutions as ‘centres of excellence’. Even though collaborative partnerships are promoted between researchers from the global north and south, there are concerns on how equitable collaborations can be attained with underlying power inequalities. Given this legacy of colonialism in Africa and the bio-power of clinical medicine, the ideals of addressing such power inequalities through community engagement in post-colonial countries need careful consideration.

The evidence presented in this section shows that the causes of mistrust with research as well as the rationale for community engagement was different in western settings and in African settings. While the rationale for community engagement in Europe and USA was to rebuild trust due to failed scientific projects, the legacy of colonialism, power inequalities, misrepresentation of study information and perceived negative experiences of interventions contributed to mistrust and the need for engagement in African settings. Given that community engagement was initiated by activists in western settings and introduced in non-western settings by researchers, this raises questions on the feasibility of attaining equitable collaborative partnerships in countries with a history of colonialism and unequal power relations. In addition, the feasibility of promoting community participation in settings with low expectations of collaborative partnerships with researchers has not been adequately explored in the literature. In the next section, I present the literature on participatory research in order to draw lessons on successes and challenges.

2.3 Participatory research

Community participation or participatory processes of involving communities have a long history in rural development but relatively new in global health research. The main purpose of introducing participatory processes in rural development was to empower communities to

identify solutions to their challenges, without external influence from outsiders (Chambers, 1997). Participatory research aims to empower local people to develop a critical consciousness of the sources of their oppression and to determine the best actions to improve their lives. According to Freire (1972 p.27), the perception of people who have been oppressed is often impaired by their immersion in the reality of oppression, such that they adapt and resign to the structure of oppression. Changing the consciousness of the oppressed through 'banking model of education' or paternalistic social protection leads them to be easily colonised or dominated. In order to transform their situation, the oppressed must participate in the revolutionary process with an increasingly critical awareness of their role as co-producer of knowledge (Freire, 1972). Thus, participatory research was introduced to link research with empowering education and action (Korrie, 1995).

While positivist research designs have been critiqued for privileging the voice of research experts; participatory research was introduced to decolonise research by incorporating locally defined priorities and perspectives. Involving local people in research was seen to empower local people to identify locally relevant solutions and to promote mutual benefits of research. Thus, participatory research emphasizes on reflexive, iterative and flexible bottom-up processes focusing on locally defined priorities (Cornwall and Jewkes, 1995). Some of the approaches used to promote community participation include: Participatory Rural Appraisal (PRA), Participatory Action Research (PAR) and Participatory Research (PP). PAR approaches thus gained popularity and support in the 1980s and 1990s from international development agencies such as USAID and generated insights of policy relevance (Chambers, 1997). Since then, PRA has been widely used by various NGOs in low resource settings to influence the research agenda and increase the capacity of local communities to improve health, food security, water and sanitation and urban poverty.

Despite the successes of these participatory processes to empower local communities to initiate positive change, several challenges have been reported. Firstly, there are questions around inclusiveness. Since development practitioners often involve few selected community members, there are risks that views of the most vulnerable and disadvantaged populations such as the elderly may be excluded. Processes of seeking consensus also risk coercing participants to follow certain view points while silencing contrary views. In addition, Ilan (2002) reported that the assumption that local knowledge should be utilized in decision making may be problematic in patriarchal communities that prohibit women from inheritance or land rights. According to Ilan (2002) relying on local knowledge in such cases may legitimize oppression of some groups in the community.

Secondly, there are also questions concerning the genuineness of the participatory process and power relations between facilitators and participants that may affect what is shared or learnt. While PRA principles stress that facilitators have to empower participants, this reversal of power appears problematic because pre-existing power relations between facilitators and participants cannot be minimized through dialogue (Ilan, 2002). For instance, the presence of outsiders may constrain some people from expressing their views and they may encode them by saying what is expected of them (Ilan, 2002). In the same vein, a study from a western context reported challenges that local community members proposed strategies that were already being implemented or that did not align with policy directions (Nimegeer et al., 2006). In addition, Mosse (2006) reported experiences in India that "*practice often contradicted the prescriptions of participatory project design because staff and villagers worked hard to sustain and protect official interpretations of action, so that they articulated with DFID policy...*". Ethnographic accounts of such malpractices were however objected by staff out of fear that they may damage the reputation of powerful institutions and individuals (Mosse, 2006). This shows that power relations between

researchers and communities may still determine how the participatory exercise is conducted, community's response to the participatory exercise as well as how to use the information generated from the PRA exercises.

Considering all of this evidence, questions still remain if participatory research has effectively decolonised the conduct of research. Thus, a review of frameworks or recommendations for practice is necessary to understand how these have been applied to improve community engagement practices. In section 2.3.1 and 2.3.2, I outline frameworks used to guide community participation in service delivery, community engagement in research and ethical research.

2.3.1 Frameworks for community participation in health service delivery

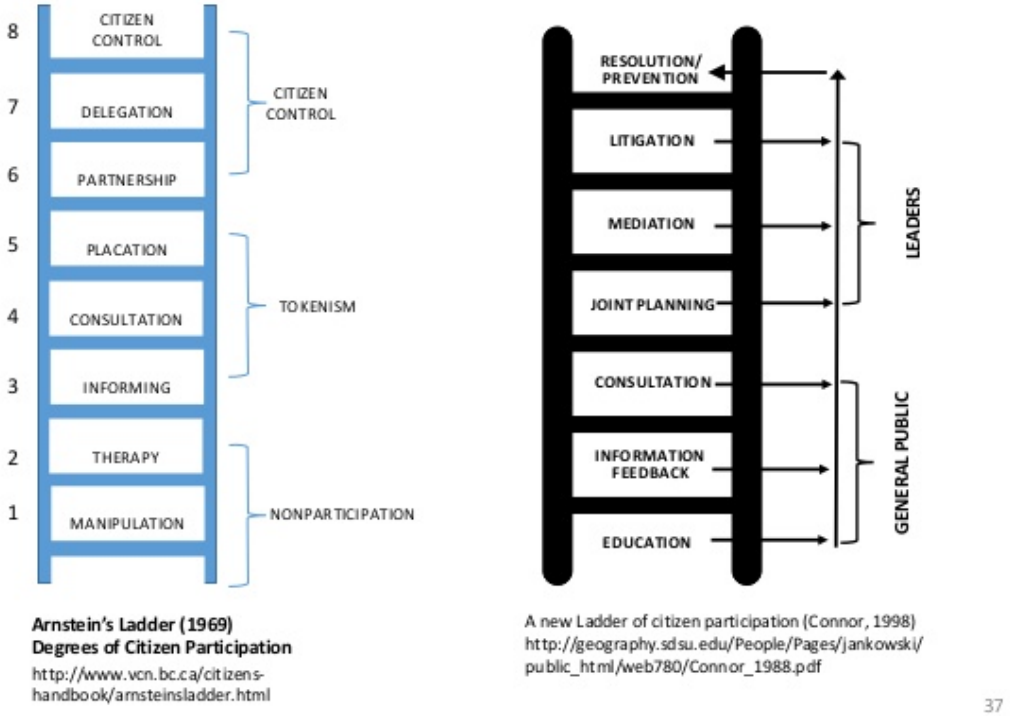
There are a number of frameworks that offer guidance on effective community participation/engagement in community development, health services and global health research. In this review, I have included nine frameworks that offer guidance on community participation and community engagement in global health. Three of the frameworks focus broadly on community participation and these include: ladder of citizen participation, new ladder of citizen participation and an institutional guideline from National Institute for Health and Care Excellence. The remaining six frameworks focus specifically on community engagement and ethical research in global health research. Despite using different terminologies to describe the frameworks, the common similarities between them are the underlying values of participatory governance. Participatory governance is an approach that is meant to engage people who are affected by a problem in the process of solving it (Lee, 2013).

While community participation is advocated in international declarations such as the Alma Ata to empower communities to improve its health (World Health Organisation., 1978), the

level of community participation is critical to effectively empower a community to address its challenges. Sherry Arnstein in 1969 categorized degrees of participation into eight levels ranging from nonparticipation to citizen control (See figure 2.1). Nonparticipation occurs when local people are involved to be educated or when they are in 'rubberstamp' advisory committees with an intention to educate them, get their support or cure them. Along the continuum is 'tokenistic' or 'cosmetic' participation where local people are informed or consulted but they lack power to influence decisions. While citizen power is attained when local people are actively involved in planning, designing and have power to influence decisions (Arnstein, 1969). This implies that meaningful engagement occurs when all parties effectively participate in discussions to identify solutions. Arnstein however acknowledged limitations that may affect community empowerment such as: diverse views among stakeholder groups, racism, resistance from power holders, ignorance and difficulties to organize representative groups to voice grievances.

In a follow up publication in 1988, Connor proposed a new ladder to overcome the limitations cited by Arnstein and resolve public controversy about projects (Connor, 1988). In the new ladder of citizen participation, the bottom three rungs of the ladder included activities targeting the general public while the top rungs of the ladder included activities aimed at leaders. The bottom rungs of the ladder proposed educating the public through existing education resources, seeking feedback in order to assess knowledge levels or identify myths, and consulting general public if an education program fails to yield informed support or when feedback is considered insufficient to adopt proposed solutions. The top four rungs included joint planning with people who have legal jurisdiction over a setting, involving neutral or third-party people to mediate conflicts, litigation and then finally resolution or prevention (See figure 2.1).

Figure 2.1: The ladder of participation and the new ladder of participation



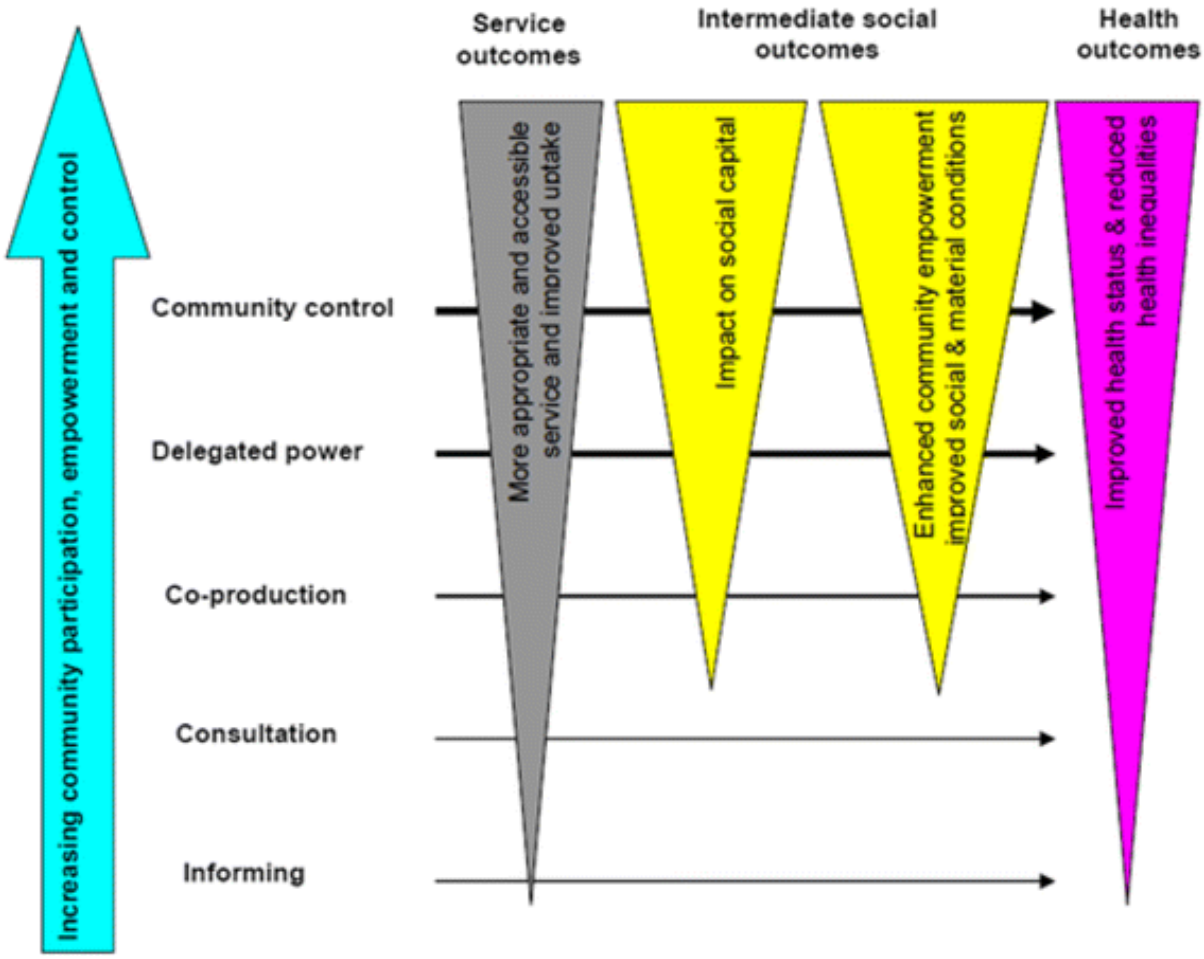
[1]

In addition to this, some institutions such as NICE also developed guidelines to guide community engagement processes in public health services in the UK (National Co-ordinating Centre for Public Engagement, 2010). Similar to the ladder of participation, these guidelines also specify different levels of community engagement as well as a range of outcomes on improving health. In brief, the guidelines indicate that approaches that involve informing or consultation have marginal impact on people's health compared to approaches

[1] https://www.google.com/search?biw=1025&bih=476&tbm=isch&sa=1&q=connor+new+ladder+of+ccitizen+participation&oq=connor+new+ladder+of+citizen+participation&gs_l=psy-ab.12...16558.18005.0.19918.4.3.1.0.0.0.274.531.2-2.2.0....0...1.1.64.psy-ab..1.0.0.Bh

that involve higher levels of participation such as: co-production, delegated power and community control (See figure 2.2 below).

Figure 2.2: Pathways from community participation, empowerment and control



https://www.nice.org.uk/guidance/ph9/…/community-engagement-final-scope2

2.3.2 Frameworks for community engagement in global health research

Other publications offered specific guidance on how to ensure effective community engagement, educate researchers and evaluate research that engages with the community. Based on published reports, James Lavery and others proposed 12 points to consider for effective engagement that are not grounded in principles of participatory governance (Lavery et al., 2010). The 12 points included: rigorous site selection, early initiation of community

engagement activities, providing information, understanding community perceptions about the proposed research, maximizing opportunities for stewardship, ownership and shared control by the community and others (see table 2.2). In contrast to Lavery's recommendations, another publication outlined a framework grounded in values around participatory governance in order to increase accountability and equality between research partners (Ahmed and Palermo, 2010). This framework offered 13 values alongside proposed strategies to accomplish each value and intended outcomes. The publication also outlined criteria for reviewing applications for research involving communities. Some of the values promoted in this framework included: having mutual understanding of the meaning of community engagement, strong partnerships, equitable sharing of power and responsibilities, inclusion of diverse perspectives, relevant research goals, ensuring mutual benefit for all partners, capacity building for both partners, equal respect, continuous communication, transparent monitoring, evaluation and others (See table 2.2). In order to measure levels of community participation in research, Kodyakov developed the Community Engagement in Research Index (CERI) to capture levels of community participation throughout the research cycle. Based on 12 specific activities focusing on involvement in grant proposal writing, study design, study implementation, data collection and analysis and dissemination of results in journal articles and conferences. Community participation is measured against each activity by indicating whether community was actively engaged, consulted or if they did not participate (Khodyakov, 2012). The CERI tool therefore offered an opportunity to measure multiple dimensions of community engagement throughout the research process.

Table 2.1: Frameworks for community engagement in research

Points to consider for effective CE (Lavery et al., 2010)	Values in CE (Ahmed and Palermo, 2010)
• Rigorous site selection • Early initiation of CE • Build knowledge of the community • Ensure goals of research are clear to community • Provide information • Establish relationships • Understand community perceptions • Identify community assets and capacity • Maximize opportunities ownership and shared control • Ensure adequate opportunities and respect for dissenting views • Secure permission from communities • Review, evaluate and modify engagement strategies	• Investigators and communities understand what CER means • Community-investigator partnership is strong • Communities and investigators share power and responsibility equitably • Diverse perspectives & populations are included in an equitable manner • Research goals are clear and relevant • Research project results in mutual benefit • Partners have opportunities to build capacity • All partners receive equal respect • Communications are continuous • Monitoring & evaluation is transparent • Partners establish appropriate policies regarding ownership • Partners translate findings into policies • Partners sustain the relationship

In addition, a number of publications have also provided guidance on how to ensure ethical conduct of research in developing countries through community consultation, community engagement and collaborative partnerships. Emmanuel (2004) proposed nine ethical principles to guide conduct of clinical research in developing countries and these include: developing collaborative partnerships, enhancing value of research to beneficiaries, ensuring scientific validity, fair selection of study population, favourable risk benefit ratio, independent review, informed consent and respect for participants or study communities. Dickert (2005) also proposed an ethical framework for evaluating adequacy of consultation based on the principles of improving protection, improving benefits, legitimacy and shared decision making. As already mentioned in the introduction, further guidance has also been provided by World Health Organisation (WHO) on community engagement and collaborative

partnerships in health research. A summary of the international ethical guidelines on community engagement include:

- Proactive and sustained engagement with communities; an ongoing process with an established forum for communication between researchers and communities
- Engagement at the earliest opportunity before study implementation to consult communities on research priorities and preferred trial design
- Transparent and collaborative processes involving a wide range of stakeholders- ensure that all voices are heard, and that pressure is not exerted by community members with greater power
- Strengthening local ownership of the research

Overall, these publications offer guidance on engaging communities, evaluating engagement processes and ensuring ethical conduct of global health research. While the first three frameworks offer guidance on community participation in service delivery, the last six frameworks offer guidance on community engagement and ethical conduct of global health research. Common to most of these frameworks on community engagement, are values from participatory governance which emphasize participatory processes of involving communities as partners rather than research subjects. In the case of global health research, this implies shared decision making in research design and implementation and promoting mutual benefit. In the next section, I review some of the approaches used to engage with communities in view of these frameworks on community engagement. Thereafter, I summarize common challenges reported in community engagement literature.

2.4 Community engagement approaches in health research

A number of approaches have been employed across different settings to engage communities in the conduct of health research. Different authors have categorized community engagement approaches differently based on the intended outcomes of engagement or levels of control by researchers or community partners (Khodyakov, 2012). In this review, I start by reviewing approaches that involve high levels of participation such as: CBPR, PPI, CABs/CAGs and finish with approaches that involve low levels of participation such as information sharing activities. By reviewing literature on community engagement approaches used across different settings, I expect to show diverse experiences of using such approaches, existing gaps in the literature and my contribution to the literature.

2.4.1 Community Based Participatory Research (CBPR)

Community Based Participatory Research is a partnership approach between researchers and community that promotes active involvement of communities in all stages of the research and all partners share decision making power, authority and ownership of the project (Morin et al., 2003). According to Freudenberg and Tsui (2014), these approaches began in the 1980's and 1990's to engage communities affected by a problem to initiate changes. The goals of CBPR were to improve ethical research practice by ensuring that the research is relevant and beneficial to communities as well as to empower communities to address their health problems (Blumenthal, 2011). Other similar approaches to CBPR include: participatory action research, action research, participatory research, community centered research, community engaged research and community partnered participatory research (Blumenthal, 2011). CBPR are often used to develop public health interventions and there is little published data of using these in the context of clinical trials or randomized control trials (Salimi et al., 2012).

Despite existing evidence of CBPR approaches to promote knowledge exchange, uptake of interventions (Cyril et al., 2015) and to improve community health (Salimi et al., 2012), numerous challenges and ethical dilemmas have been highlighted. Some of the challenges reported in the literature include: difficulties to attain equitable participation, difficulties to balance requirements from funders and community priorities, lack of commitment from community partners, difficulties to identify legitimate community representatives and evolving community priorities or leadership structures (Blumenthal, 2011). Other ethical dilemmas pertain to challenges to safeguard privacy and confidentiality of participants and minimizing harm to participants whose identities may be hard to conceal from other community members (Banks et al., 2013). Much uncertainty therefore still exists whether community partners and researchers should play equitable roles in every phase of the research or in all study designs.

2.4.2 Patient and public involvement in research (PPI)

Patient and public involvement in research share similar ideals with CBPR in that collaboration, shared decision making and shared ownership is promoted among research stakeholders (Gillard et al., 1999). This approach was informed by principles that underpin the Science and Society model that "*people affected by research should have a say in how research is undertaken"* (Staley, 2009). As such, PPI aims to promote co-production of knowledge by conducting research with patients or members of the public and not solely on them. Contrary to CBPR, a majority of studies involving PPI have been conducted in developed countries such as UK, United States and Canada. Partly, this could be due to regulatory requirements from the government or funding bodies. For instance UK NHS states that "*relevant service users and carers or their representative groups should be involved wherever possible in the design, conduct and reporting of research*" (Department of Health., 2005).

Studies involving PPI in western settings have demonstrated benefits as well as challenges. Despite the growing body of literature on PPI, evaluating impact of PPI has been challenging due to variations in the context, research topics and quality of involvement (Staley, 2015). As such, the evidence that demonstrates benefits of PPI is described as weak. Some of the benefits of PPI reported in the literature are that it improves the quality and relevance of research to participants, informed consent as well as recruitment (Ives et al., 2013, Brett et al., 2014, Dudley et al., 2015, Johnson et al., 2016). Challenges however are that incorporating lay perspectives in research design present difficulties to comply to scientific procedures, lay representatives feel inferior to make contribution, it is challenging to safeguard participants confidentiality, lay perspectives are sometimes dismissed by researchers, retention of lay members is challenging and that it is time consuming and costly (Brett et al., 2014, Gillard et al., 1999). Ives (2013) has also critiqued the democratic ideals promoted in PPI as risky by *"putting unskilled people in positions where they can control processes they understand little"* (Ives et al., 2013). Overall, there seems to be some evidence of benefits of PPI. A majority of the publications however have reported benefits from the perspectives of researchers. There remain several aspects of PPI about which relatively little is known, such as the relevance and impact of PPI from the perspectives of research participants.

2.4.3 Community Advisory Boards (CABs) or Community Advisory Groups (CAGs)

Establishment of Community Advisory Boards or Community Advisory Groups is another approach of engaging community representatives in research. CABs were introduced in health research to enhance collaboration between researchers and communities or strengthen representation of participating communities in research planning and implementation in order to enhance ethical research practice (Cox et al., 1998, Ross et al., 2010b, Strauss et al., 2001, Quinn, 2004). As previously explained, some donors require that CABs should be established

in health research in low income settings to strengthen collaborative partnerships (Boulanger, 2013). Most countries in low income settings however do not have regulatory requirements for establishing CAGs. Rather than being engaged as community partners in research design and implementation, functions of CABs vary across research institutions in that some researchers consider them as partners who should contribute to the research design and implementation while others engage CABs to facilitate communication between researchers and community.

While engaging a CAB is designed to strengthen community engagement, existing literature demonstrates challenges. Some studies in low resource settings in Asia and Africa have reported conflicting roles of CABs to provide input in protocol development, minimize harm as well as to advance research goals by facilitating recruitment of participants (Reddy et al., 2010, Morin et al., 2003, Nyirenda et al., 2017, Pratt et al., 2015). Other challenges include limited understanding of health research, monetary expectations, dependence on researchers for finances, and lack of authority to influence decisions concerning research (Cox et al., 1998, Shubis et al., 2009, Manda-Taylor, 2013, Pratt et al., 2015). These challenges have led to skepticism about the advisory roles of CAG members and concern that their involvement is sometimes tokenistic or 'window dressing' to fulfill donor requirements (Quinn, 2004, Strauss et al., 2001).

2.4.4 Other community engagement approaches

In addition to community engagement strategies reported above, information sharing activities through community sensitization meetings, media and involvement of community leaders, community representatives and other stakeholders have also been widely reported particularly in the literature from Africa (Marsh et al., 2008a, Kamuya et al., 2013, Okello et al., 2013, Nakibinge et al., 2009, Nyika et al., 2010). An overview of some of the community engagement approaches reported in the literature has been presented in Table 2.2. A number

of empirical studies have been undertaken to evaluate outcomes of using community engagement activities in different African countries. For instance, Kamuya (2013) used a mixed methods study design to assess the role of community representatives at Kenya Medical Research Institute (KEMRI). She reported that benefits of engaging community representatives were that they helped to increase knowledge of medical research and improved community acceptability of KEMRI. Similarly other studies in Kenya, Tanzania, Uganda as well as a multi-sited study in Burkina Faso, Mali and Tanzania reported benefits of using community representatives such as Community Liaison Groups, Community Advisory Committees, Community Project Advisory board and meetings with research stakeholders to improve community understanding of research, identify community concerns and corrective action (Vallely et al., 2007, Okello et al., 2013, Nakibinge et al., 2009). These authors also reported that these approaches improved communication with communities, understanding of the trial and successful study intervention. Collectively, these studies support findings by Angwenyi (2014) that community engagement is perceived by research stakeholders as a means of clearing concerns, increasing visibility and study participation.

A majority of empirical studies have also focused on ethical issues due to these power differentials between research stakeholders. While engaging community representatives is generally seen to strengthen ethical research, some studies have reported that social relations between field workers and trial communities in the context of unequal power relations and limited access to health care compromised ethical conduct of research (Molyneux et al., 2010, Chantler et al., 2013, Angwenyi et al., 2013). Due to limited access to health care, trial communities participated in research in order to access medicines and other incentives. In addition, social relations or close proximity between field workers and trial communities also facilitated participation in research (Geissler et al., 2008, Molyneux and Geissler, 2008). For instance, field workers could influence other people's attitudes towards the study by

emphasizing the study benefits or distorting study information to encourage participation or refusals (Molyneux et al., 2010, Chantler et al., 2013, Angwenyi et al., 2013).

Despite the challenges reported in the literature from Sub-Saharan Africa, other studies from the global north and other post-colonial settings have shown successful examples where community voices have been used to influence research priorities, data disclosure strategies and to address community concerns. For instance, a study in the USA reported successful experiences of engaging native Americans in setting research priorities for health for different community groups (Goold et al., 2018). Similarly, another study in Ohio reported successful involvement of communities in developing data disclosure strategies to individual research participants to address community concerns about manganese exposure (Haynes et al., 2016). The success of these engagement activities could probably be attributed to lesser inequalities of power between researchers and local communities in developed countries. In addition, successful examples where community voices have influenced the conduct of global health research have been reported from HIV prevention trials in post-colonial settings where activists were involved. These trials were launched in 2004/2005 with funding from National Institute for Health, Centres for Disease Control, Family Health International and the Gates Foundation to investigate the safety and effectiveness of Tenofovir to prevent HIV transmission in Cambodia, Cameroon, Thailand and Nigeria. (Ukpong, 2009). Community activists in these settings however identified unethical practices in the trial design such as lack of post-trial access to Pre-Exposure Prophylaxis and lack of ARTs to participants who sero-convert (Ukpong, 2009). Failure to address these concerns through dialogue led to protests and premature suspension of the trials in Cambodia, Cameroon, Nigeria, Thailand and Malawi. Consequently, the Good Participatory Practice Guidelines were developed to improve community engagement from protocol development to dissemination of results. This example shows a positive case study where an ‘activist led’ approach rather than a

'researcher led' approach influenced changes in protocol implementation and minimized harm to research participants.

Despite the existence of numerous guidelines and frameworks on community engagement, few empirical studies sought to understand why community engagement activities did not reflect the ideals around participatory governance. Few studies also focused on understanding neo-colonial relations between research stakeholders and consequent effects on community engagement practice or study acceptability. Considering the challenges of unequal power relations in the conduct of global health research, a review of empirical studies, systematic reviews and literature reviews is necessary to understand outcomes of community engagement. In the next section, I present an overview of the themes in the literature on evaluation of community engagement.

Table 2.2: Examples of community engagement approaches used in research conducted in Africa

Country	Community engagement activities
Ghana (Tindana., 2011)	Community entry activities Explaining the study to paramount chiefs Seeking permission to approach other members of community
Kenya (Marsh et al., 2010, Marsh et al., 2008a, Kamuya et al., 2013)	Training of field workers on communication and participants rights in research Consultation with chiefs-providing information Assessing chiefs perceptions and attitudes Asking for their recommendation Community/public meetings to share study information and respond to questions Selection of community representatives through CBOs to strengthen communication between researchers and community Feedback community views

	Increase community understanding of research Distribute IEC materials
South Africa (Ntshanga et al., 2009)	CAB Discuss TB related issues such as education and awareness programmes Identify gaps, come up with plans and programme of action
Tanzania (Shubis et al., 2009)	CAB Feedback community concerns, assist in disseminating results and information, enhance consenting and follow up processes in clinical trials, manage false rumours, and crisis management

2.4.5 Evaluation of community engagement projects

The increasing emphasis on community engagement in research necessitates the need for effective community engagement approaches. Few empirical studies have however been undertaken to evaluate the impact of community engagement in African settings and these studies have focused on specific models of community engagement such as CABs (Morin et al., 2003), community liaison systems (Shagi et al., 2008), community representatives (Kamuya et al., 2013), CBPR and CEnR (Hicks et al., 2012, Akinwale et al., 2014) leading to gaps in the literature on feasibility of attaining equitable collaborative partnerships in neo-colonial settings.

To date, a growing body of literature reviews have been undertaken to understand the impact of community engagement on specific outcomes or topics such as population coverage (Adhikari et al., 2016), mental health services (Khodyakov et al., 2012), child survival (Farnsworth et al., 2014), HIV infections (Laurie Ackerman and Karusa, 2012), health services (George et al., 2015, Rifkin, 2014), health outcomes (Cyril et al., 2015, O'Mara-Eves et al., 2015) and health research (Musesengwa and Chimbari, 2015, Tindana et al., 2015).

These studies provided evidence that community engagement improved population coverage of malaria interventions (Adhikari et al., 2016), behaviour change to enhance child survival (Farnsworth et al., 2014) and other impacts in the community (Khodyakov, 2012). Some of the factors that were associated with these positive outcomes pertain to participatory processes such as collaborative partnerships, shared leadership, power sharing, mutual learning and incorporating the voice and agency of beneficiary communities (Farnsworth et al., 2014, Cyril et al., 2015).

On the other hand, variations were reported on the impact of community engagement on health outcomes and health services across different contexts. For instance, a systematic review based on studies from the UK indicated that there was no evidence of positive impacts on population health or quality of services (Milton et al., 2011). In contrast, other reviews based on studies conducted among marginalised or disadvantaged populations reported positive effects on health outcomes (Cyril et al., 2015, O'Mara-Eves et al., 2015). These discrepancies of outcomes from developed settings and disadvantaged populations suggest that outcomes of community engagement may vary across different contexts.

In addition, two reviews that have been undertaken to identify effective community engagement strategies in health research conducted in Africa concluded that insufficient evidence existed on effective community engagement approaches (Musesengwa and Chimbari, 2015, Tindana et al., 2015). Challenges to assess the impact of community engagement have been widely reported (Tindana., 2011, Milton et al., 2011, Sieber, 2010, Tindana, 2007) due to lack of consensus on the meaning of community engagement, variations in practice, diversity in the community and research participants views, and differences in community structures and norms (Wellcome Trust). Other authors have also argued that criteria for measuring impact excludes lay perspectives (South and Phillips, 2014, Musesengwa and Chimbari, 2015) and only includes biased perspectives of researchers or

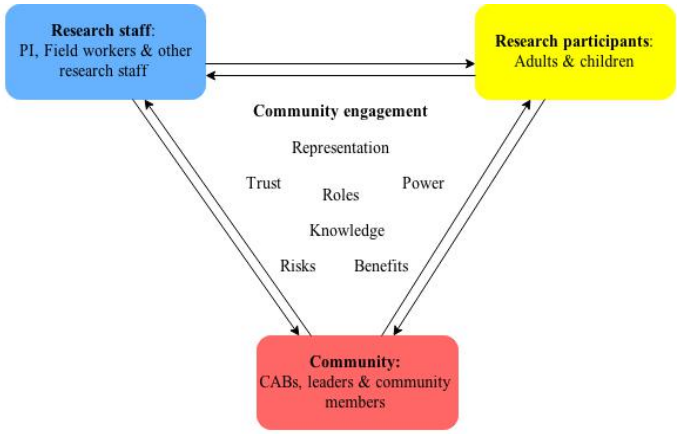
service providers. Collectively, these studies indicate the need for empirical research to understand outcomes of engaging communities from multiple research stakeholders across different contexts and study designs. In the following paragraph, I present my initial conceptual framework which was used to design the research and address this knowledge gap.

2.4.6 Initial conceptual framework

I developed an initial conceptual framework (Figure 2.3) to guide the development of this research and to address the research objectives presented in section 1.1. As previously indicated in this literature review, community engagement is promoted in international research to promote collaborative partnerships and ethical research practice. I have however shown that there are unresolved debates on how to ensure fair representation of communities and overcome power imbalances which potentially limit marginalised communities from negotiating decisions with researchers. In addition, I also indicated that there are challenges to evaluate community engagement due to variations in meanings and practices leading to gaps in literature on the rationale and outcomes of these (Bauer et al., 2007, Tindana., 2011). In this research, I sought to understand factors shaping community engagement practices and explore the relevance, benefits and risks of engaging with communities. I did not plan to use theories of neo-colonialism to analyse community engagement in medical research when designing the study. Rather, theories of neo-colonialism were applied in later stages of data analysis and interpretation to explain the absence of the ideals of collaborative partnerships. Figure 2.3 is an initial conceptual framework for the study. The triangle illustrates research stakeholders involved in community engagement including: research staff, research participants and community. According to the literature review, the needs for engagement among the three stakeholders are diverse and hence the need to improve dialogue and relevance of the research to all parties. In order to answer the research questions, I aimed to

understand how neo-colonial relations between research stakeholders shape community engagement, ethical research and study acceptability.

Figure 2.3: Initial conceptual framework



2.5 Conclusion

In this literature review, I have presented multiple interpretations of community engagement, models of health and bio-power, historical developments in relation to public engagement, history of medical research in Africa, ethical reasons for engaging communities in research, participatory development, frameworks used for community engagement, dilemmas experienced and challenges to evaluate community engagement. The studies reviewed support the notion that the term community engagement has multiple interpretations. In addition, community engagement needs and approaches differ across different contexts and there is limited evidence on how these strengthen collaborative partnerships.

This review has shown that factors leading to increased support for community engagement are diverse across western and African settings. While the need to engage communities in research in western settings was partly 'public/community driven' to promote co-production of knowledge, studies in African settings have shown that community engagement was

'researcher driven' to strengthen relationships, improve recruitment of research participants and informed consent. Various frameworks have been developed to guide or evaluate community engagement in health service delivery and health research across different settings, however challenges remain on how to engage communities in participatory processes. An understanding of the historical, political and socio-economic context is therefore necessary to understand factors that shape community engagement practice and outcomes. In the following chapter, I will describe the context where this research took place.

Chapter 3: Context

3.1 Introduction

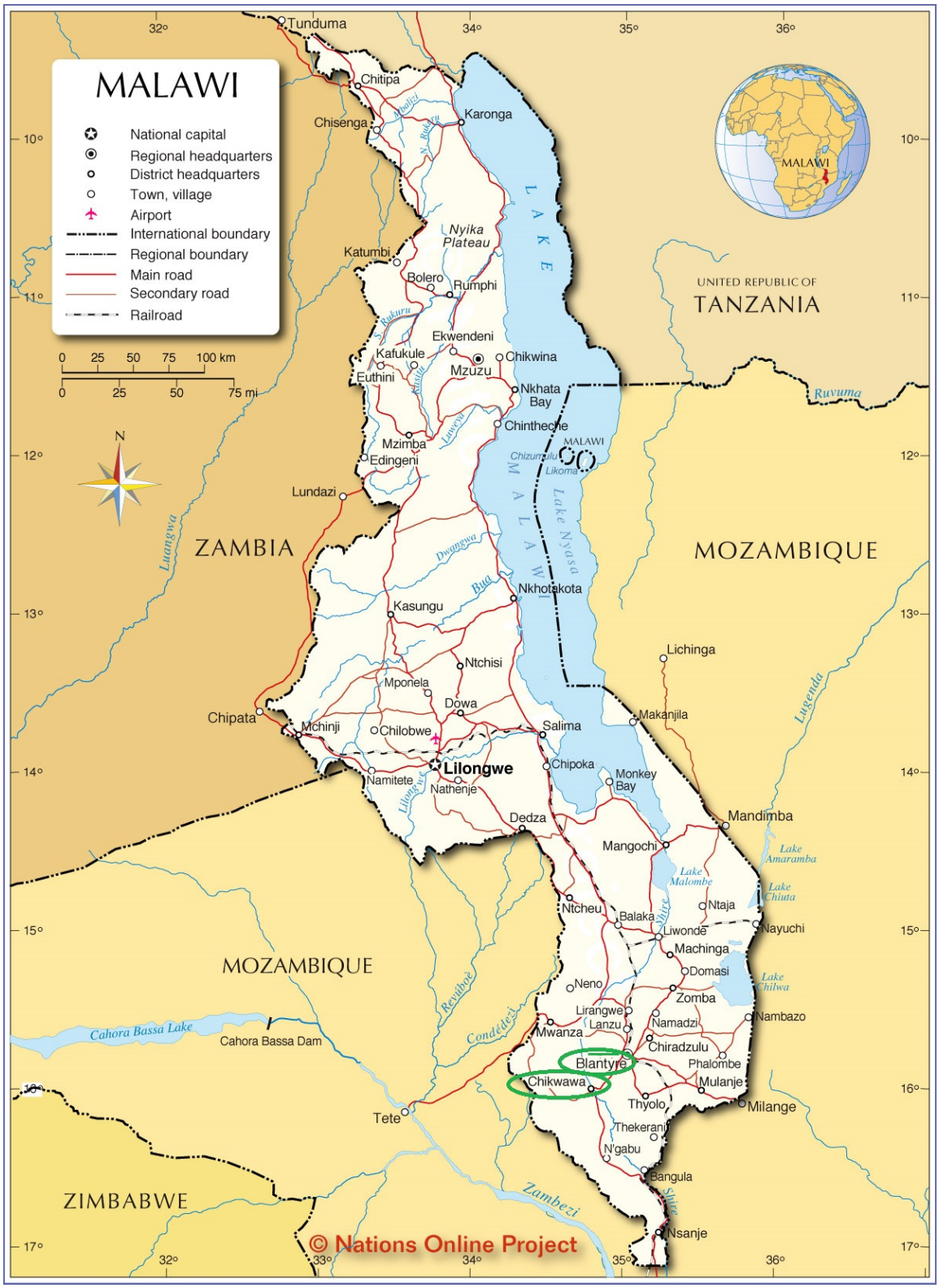
Africa is faced with a huge disease burden due to HIV/AIDS, lower respiratory tract infections, Malaria and Tuberculosis amongst others. Nwaka (2010) reported that Africa has up to 90% of the global disease burden despite representing only 15% of the global population. Treatment and vaccines for these conditions are however unaffordable and inadequate for large populations. Research for diseases affecting developing countries is also considered inadequate (Nwaka et al., 2010) and mostly focusing on HIV/AIDS, Malaria and Tuberculosis. To date, only 31% of clinical trials in Africa are related to diseases that account for approximately 50% of the African disease burden (Nwaka et al., 2010) and this necessitates the need to strengthen health research capacity in order to address public health challenges. Lack of funding from local governments and shortages of human resources however affect research productivity in Africa to improve health (Nachega et al., 2012). As such, most of the funding for research comes from external sources such as Wellcome Trust, NIH, DFID and CDC leading to increased international collaborations on global health research programs.

Malawi is one of countries located in the southern part of Africa that implements global health research projects with financial support from international donors. The country is divided into three regions: north, central and south and further sub divided into 28 districts. This study was conducted in Blantyre and Chikwawa districts in southern Malawi (See figure 3.1). Blantyre is an urban district and Chikwawa a rural district in southern Malawi where COM and MLW are implementing the majority of their research projects. The total population in Malawi is 17,215,000 and a majority of people (84%) reside in rural areas (The

World Bank., 2016). There are a number of ethnic groups in the country such as the *Chewa, Lomwe, Yao, Ngoni, Tumbuka, Tonga, Nyanja, Sena* among others and each of these groups have their own traditional leadership structures and languages. Chichewa is however the common language in Malawi while English is the official, national language.

In this chapter, I will describe the context which is relevant to understand how communities engage with researchers. Since the conduct of international medical research is influenced by colonial history as well as the economy (Geissler, 2011), I will start by describing the historical, political and socio economic context (3.2), health service delivery and research (3.3), thereafter I will give a comparison of the study sites (3.4), and the three case studies (3.5). After providing this background information, I will describe the methodology in Chapter four.

Figure 3.1: Map of Malawi



Source: http://www.nationsonline.org/oneworld/map/malawi_map.htm

3.2 Historical, political and socio-economic context

An understanding of the historical, political and socio-economic context is necessary to understand how communities engage in health research. I will therefore provide key events in the history of Malawi in relation to themes of medicine and governance from the pre-colonial, colonial and post-colonial periods.

3.2.1 Pre-colonial and colonial historical context

Malawi was previously called *Maravi* kingdom. The country was inhabited by different ethnic groups governed by their own chiefs who were normally appointed by following a family inheritance system. Most of these ethnic groups shared similar religious beliefs and practices. For instance, they believed in the existence of a great spirit or creator often called *Chiuta.* Outbreaks of epidemics and other calamities such as drought and famine were interpreted as visitations from the spirits because the community had angered the gods (Phiri, 2004). The angry gods were appeased by offering them prayers and sacrifices such as meat and beer. Traditional healers would offer *zithumwa* [talisman], *nyanga* [horn], *mphini* [tattoo marks] and other traditional medicine to prevent misfortunes including illnesses, sorcery and thefts (Lwanda, 2005). The *mphini* [tattoo marks] were also used to administer herbs directly into the blood stream while other herbs were taken orally. In order to diagnose illnesses or the cause of misfortune, rituals involving flywhisks, gourds, rattles and bones [*maula*] were used to determine the causes (Lwanda, 2005).

In the mid 18th Century, Portuguese and Arab traders started entering the country following a great demand for ivory and slaves on the East African markets. The slaves were mainly used to work in plantations owned by Portuguese in Mozambique and Brazil. The Arab slave traders converted some tribes to Islam particularly along the southern coast of the lake. Later on, Christian missionaries such as Dr David Livingstone also visited the country and observed that slave trade, tribal conflicts, starvation and diseases were rampant. As a result,

the Christian missionaries established their first missions in order to abolish the slave trade, introduce Christianity, commerce, western civilization and biomedicine. To date, Christianity remains the predominant religion (80%), followed by Islam (12%) (National Statistics Office., 2008) while the country remains one of the poorest in the world.

Between 1891 and 1963, Nyasaland became a British colony under the leadership of Harry Johnstone (McCracken, 2012). During the colonial period, western education, bio-medicine, technological advances and new political systems begun to spread out. The country was divided into districts governed by expatriates and districts were divided into sections that were further sub divided into villages. The District Commissioner appointed Principal headmen to be in charge of the section while village headmen were in charge of the villages. This system of appointing tribal or community leaders is still present to date and local chiefs play an instrumental role in the conduct of medical research by giving community consent for a study to be conducted in their village.

During the colonial period, colonial leaders designated powers to local chiefs to assist with administrative issues such as collecting hut taxes and infrastructure development (Ross, 2009). This system of delegating power to local chiefs led to the formation of Native Associations tasked with responsibilities of preserving social order and enforcing some of the demands from the European administrators across the country. Despite the reforms to include Africans in political decision making, the colonial government was still seen to promote the interests of the whites and not Africans. In addition, the colonial period is marked in the history of Malawi as an oppressive period because military force was used to conquer villages by assassinating chiefs or setting their villages on fire if they were resistant to British rule. Most of the local people were also forced to work under harsh conditions in plantations owned by Europeans because hut taxes were imposed on local people to be paid to the government in labour or food stuffs. Refusal to pay hut taxes led to assassination of people

and destruction of villages. The European settlers were also seen to exploit local people by occupying the best arable land which previously belonged to locals in addition to engaging them to fight during the First World War. Thus, experiences from the colonial period are seen to have shaped perceptions of Europeans as superior and local people to view themselves as inferior (White, 1984) as well as resentment against the colonial rule. Consequently, local people protested against the colonial rule and Dr Kamuzu Banda became the first head of state after gaining independence in 1964.

3.2.2 Post-colonial historical context under the one-party rule (1964-1994)

Dr Kamuzu Banda was the first head of state from 1964 to 1994. During this time, he continued to develop public infrastructures introduced by the colonial leaders such as railways, public health facilities, schools and universities. Dr Banda was however an autocrat who did not tolerate any criticism or complaint against his ideas or government. As such, anyone seen as an opponent was tortured and murdered. Membership in his party was made compulsory, every person residing in urban locations was supposed to have a party membership card in order to board public buses or enter the market (Phiri, 2010). During his time, stories, poems, songs and plays were censured to ensure that they were praising Banda while women were expected to chant songs of praise about his great works during public rallies. As such, experiences from the colonial rule and autocratic leadership of Dr Banda led to fears and a 'culture of silence' among Malawians to express critical views to authorities (Manda, 2002).

In 1968 there were reports of the serial killing of people in some of the townships in Blantyre (Phiri, 2010) which led to rumours in relation to blood stealing and witchcraft. Dr Banda was believed to have ordered the murders in order to obtain blood which was used to service a loan from South Africa. Banda however dismissed these rumours by telling people during public rallies that *afiti* [witches] were killing people in order to use the blood for witchcraft.

To date, some communities still associate blood drawing with devil worshiping or witchcraft, and this affects community's perceptions of medical research that draws blood from people. According to Mfutso-Bengo (2008 p.59), people refuse to participate in research that involves drawing blood because of beliefs that 'blood is a weapon used in witchcraft to inflict pain or send pestilence to people'.

Due to social injustices and a worsening economy during Dr Banda's reign, Catholic Bishops issued a letter to the president calling for democratic reforms. Following this, donors suspended aid to Malawi in order to force the president to improve human rights. Thereafter, students from the University of Malawi staged demonstrations calling for democratic reforms and there were mass riots and protests from employees in different organisations demanding better wages. Due to pressure from western countries, international partners and national protests, Dr Banda called for a referendum where a majority voted for multiparty democracy in 1994.

3.2.3 Government and politics in the democratic era (1994 to date)

Despite the changes in leadership from an autocratic to a democratic government, most of the democratic political parties have been critiqued as lacking distinctive features in relation to democratic principles (Chiweza, 2007). As such, I will present a general overview of government and politics during the democratic period. My focus however will be on citizen participation in decision making since this may influence community participation in health research.

After voting for multiparty democracy in 1994, Dr Bakili Muluzi from United Democratic Front (UDF) became the second head of state. Thereafter, his successor Bingu wa Mutharika from UDF won the elections in 2004. Later on, Bingu defaulted to form his own political party called the Democratic Progressive Party (DPP). Bingu wa Mutharika stayed in office

for eight years and died in 2012 while he was still president. His vice president, Dr Joyce Banda stepped into power in 2012 but she also defaulted to form her own political party called the Peoples Party. Dr Joyce Banda served for two years before losing the elections in 2014 to Bingu wa Mutharika's brother Arthur Peter Mutharika. Prof. Arthur Peter Mutharika from DPP is now the current president of Malawi.

More generally, the state of democracy in Malawi has been described as 'a culture of chameleon politics' (Englund, 2002) because most of the leaders keep shifting their political affiliations to join the ruling party in order to access resources for their own personal benefit. In addition, Gaynor (2010 p.805) described the democratic state in Malawi as being ‘marked with hierarchical structures of social relations, incorporating clientelist mechanisms of legitimacy and exchange, coupled with a strong authoritarian strain’. While ordinary citizens were being forced to give monetary or material gifts to Dr Kamuzu Banda, political leaders during the democratic period give out monetary and material handouts to ordinary citizens to buy their votes (Tambulasi R, 2005). This political culture has led to a ‘dependency syndrome’ which affects successful implementation of democratic reforms as well as voluntary participation in research projects.

A constitution with democratic principles was developed in 1994. The constitution made provisions for citizen participation in the election of key leaders in decision making positions. The president is elected through popular ballot to serve for five years while cabinet ministers are appointed by the president to oversee government departments. Voices from the citizens are heard through elected representatives commonly known as Members of Parliament (MP) and local government councillors. Members of Parliament and local government councillors are elected by residents in specific geographical locations. The counsellors are tasked with responsibilities of representing the community's interest at the local assembly level and to the

MP. On the other hand, the MPs represent community's interests at the national assembly as well as national interests by deliberating on bills.

In order to strengthen citizen participation in decision making, reforms were made to local government through the decentralisation program. The decentralisation program transferred power and responsibility from the central government to the local assembly in each district. The local assemblies are headed by the mayor in cities or the chairperson of the assembly in districts. Each district has government offices such as the District Health Office and District Education Office responsible for service delivery and reporting local development plans to the central ministry. In addition to the district offices, local assemblies are also supposed to have committees for health and education that deal with specific issues.

At the grassroots level, Village Development Committees (VDC) and Area Development Committees (ADC) offer structures to promote community participation. Every district is divided into wards that are headed by a Traditional Authority (TA). The wards are made up of several villages headed by a Group Village Headman. Each village is headed by a Village Headman who reports to the Group Village Headman. Village Development Committees are comprised of elected representatives from specific villages, councillors, representatives nominated by people and extension workers. The ADC is a representative body for all the VDC under the jurisdiction of a TA which includes representatives from VDC and other representatives from religious, youth and women's groups. Responsibilities of the VDC and ADC are to identify development needs and present local development plans to the local assembly.

Despite the existence of these structures to promote democratic participation of community members in development, there are challenges to attain this because guidelines on composition of VDC and ADC are not always followed. While democratic principles

emphasize democratic elections of representatives, most of the VDC and ADC are made up of chiefs who appoint themselves. In addition, traditional leadership systems are also in conflict with bottom up democratic principles because they support top down approaches and the chief's word is often considered as final (Chiweza, 2007). As such, the hierarchical, authoritarian and clientship political culture in Malawi is in conflict with the ideals of participatory governance (Gaynor, 2011). Consequences of 73 years of colonial rule and 30 years of dictatorship is seen to have created a culture that does not promote democratic values to encourage public participation and tolerate divergent views (Magolowondo, 2007). This culture affects community perceptions of community engagement and international collaborations in research.

3.2.4 Social economic context

Some of the leading determinants of poor health outcomes in Malawi are low levels of education and poverty. Malawi is a low income country with over 72% of the population living below the poverty line of less than USD 1.25 a day (United Nations Development Programme., 2015). The country's economy is largely dependent on agriculture with tobacco, sugar and tea as the main export products. More than 85% of the population depend on subsistence agriculture (World Bank, 2014), and the main food crops grown for consumption include maize, cassava, sweet potatoes and vegetables. A majority of the population who engage in agricultural work reside in rural areas (National Statistics Office & ICF Macro, 2011).

Literacy rates are relatively high at 65% (National Statistics Office., 2012) however the quality of education remains poor due to shortages of teachers, classrooms and teaching materials (Chimombo, 2005). Despite offering free primary education in public schools, dropout rates are high due to poverty and consequently, only16% of the population complete secondary education (United Nations Development Programme., 2015). According to the

Malawi Demographic and Health Survey report (2010), a higher proportion of school drop outs are children from rural areas compared to children from urban areas. In addition, more boys from urban settings tend to complete secondary education (10-17%) compared to girls (2-4%) (National Statistics Office & ICF Macro, 2011). This has resulted in higher literacy levels among men compared to women and higher literacy levels in urban areas compared to rural areas.

Due to low literacy levels and poverty, radio is a popular source of information followed by television and newspaper. Over 62% of the population own radios compared to 47% of the population who own a television (Malawi Communications Regulatory Authority., 2015). Access to information through social media is limited with only 7% of the population having access to internet services (Malawi Communications Regulatory Authority., 2015). Lack of knowledge to use the internet and high costs of internet services prevent most people from using the internet. Mobile phone ownership is however high at 85% (Malawi Communications Regulatory Authority., 2015) and some people access radio information through their mobile phones.

Malawi faces a huge disease burden with high rates of both communicable and non-communicable diseases such as HIV/AIDS, lower respiratory tract infections, malaria, stroke and diarrhoeal diseases. Malaria is the leading cause of death among children under five years of age accounting for 14% of child deaths while HIV/AIDS is the leading cause of death among adults (World Health Organisation., 2015). Despite reductions in mortality rates from HIV/AIDS, TB and malaria between 2000 and 2012 (World Health Organisation., 2015), under five mortality rates remain among the highest in the world at 64 per 1,000 live births compared to the global average of 43 per 1,000 live births (World Health Organisation., 2016c). Similarly, despite scaling up interventions towards preventing HIV/AIDS, malaria and TB, the incidence of these diseases remains high compared to global

average rates. Worldwide, the global average incidence of malaria in 2016 was 91 per 1000 people at risk while in Malawi it was more than double at 217 per 1,000 people at risk (World Health Organisation., 2016c). While the global average incidence of TB in the same year was 133 per 100,000 people, the incidence rate in Malawi was also close to double at 227 per 100,000 people (World Health Organisation., 2016c).

The prevalence of diseases such as malaria and diarrhoea is generally higher among the poor or illiterate populations (Ministry of Health., 2011). Due to poverty, many people experience community level challenges to access timely health services due to transport and other opportunity costs (Desmond et al., 2013). While people with higher income levels have added options to pay for better treatment in Christian Health Association of Malawi (CHAM) and private facilities, most of the poor are limited to access government facilities because they provide services free of charge. In addition, most of the health facilities remain overcrowded and underfunded despite increases in total government expenditure on health from 5% to 11% of the Gross Domestic Product (World Health Organisation., 2016a). Access to quality health services in government health facilities therefore remains a challenge.

3.3 Health service delivery and research

Within this structurally challenging context there have been many health research projects conducted by both local and international institutions. In this section, I provide an overview of health service delivery, structures for community participation in health service delivery and health research in Malawi.

3.3.1 Health service delivery

There are three major providers of health care services in Malawi: Ministry of Health, CHAM and the private sector. The Ministry of Health is the main service provider responsible for developing and enforcing health policies and regulating the health sector. The

Ministry of Health offers essential health services free of charge to the public while CHAM and private hospitals charge user fees. Traditional healers offer informal health services but they have not yet been integrated into the health system.

There are three levels of health care service delivery namely primary, secondary and tertiary health care. Primary health facilities include community facilities as well as community health workers commonly known as Health Surveillance Assistants (HSA) who offer community health care including maternal and child health services. Secondary health services include district hospitals that offer specialised care to people who have been referred from primary health facilities while tertiary hospitals offer highly specialised care in central hospitals across the three regions. Despite efforts to improve access to health facilities by offering services that are free of charge, quality of health services remains poor in government health facilities due to lack of equipment, shortages of drugs and inadequate staff. According to recent statistics from WHO, the density of physicians per 1,000 population was very low at 0.018 while the density of other health service providers was also low at 0.027 per 1,000 population (World Health Organisation., 2016a). Due to poor quality of health services in government facilities, previous research has shown that a majority of people participate in research in order to access better treatment offered by researchers (Mfutso-Bengo et al., 2008b).

The Ministry of Health has outlined provisions to enhance community participation in health service delivery through Village Health Committees (VHC) and health facility advisory committees. The VHCs are responsible for ensuring that individuals participate in health promotion activities while the health facility advisory committees are responsible for monitoring drug usage and facilitating dialogue between health care workers and community. Most of these committees are however non-functional because they were not adequately oriented to carry out their tasks (World Health Organisation., 2014). In order to address this

challenge, a training manual was recently developed by the Ministry of Health in 2017 to build capacity of VHCs. According to the training manual, each village is supposed to have one VHC comprised of 10 members who have been democratically elected by community members (Government of Malawi., 2017, September). Roles of the VHCs include: investigating community challenges, disseminating health messages, promoting sanitation and teaching people about disease prevention (Government of Malawi., 2017, September).

3.3.2 Health research

History of health research

Health research in Malawi was introduced during the pre-colonial period by the white missionaries. As indicated in section 3.2.1, the European missionaries led by Dr David Livingstone came to Africa to abolish slave trade and introduce British civilization, commerce and Christianity. The European missionaries were however susceptible to tropical diseases and this affected the expeditions and claimed many lives. Dr David Livingstone therefore appointed a botanist and a medical doctor, Dr John Kirk and Dr Charlse Meller in 1858 and 1861 respectively to accompany the expedition (Hokkanen, 2012).

The first medical investigations or health research was conducted on malaria by Dr Charles Meller and results were published in the British Medical Journal in 1862 (King and King, 2007). Recommendations such as taking quinine at the onset of malaria and preventive measures such as clearing of stagnant waters, using bed nets, improving buildings were therefore promoted at this time (King and King, 2007). Meller was credited for having conducted 'the first disease survey in Central Africa on Malaria' and his journal articles pioneered contributions in the field of tropical medicine (Larner, No date). To date, more than 483 journal articles have been published by expatriate researchers as well as local

researchers on malaria in pregnancy, severe malaria and vector dynamics (Mwendera et al., 2017). Malaria however remains the leading cause of admission and mortality in Malawi as indicated in section 3.2.4.

During the pre-colonial and colonial periods, Europeans were also interested in identifying local medicines and plants from Africa for commercial development in the global north. For example, samples of an arrow poison called *Strophanthus Kombe* were collected by Dr John Kirk in Chikwawa, Malawi and sent to Europe for research (Hokkanen, 2012). After 15 years of research by Prof Thomas Frazer from University of Edinburgh, a cardiac medicine called 'Strophanthin' was developed in 1885. The sales of Strophanthin in Europe and USA led to the success and rapid economic growth of Burroughs, Wellcome & Co. pharmaceutical company. To date, fortunes made by Sir Henry Wellcome of the Burroughs, Wellcome & Co. pharmaceutical company presently fund medical research in Malawi and other low-income settings through the Wellcome Trust. This connection could paradoxically be fulfilling an ethical obligation to 'provide benefits to communities whose valuable leads have resulted in pharmaceutical and biotechnological profits' or to advance bioprospecting by 'serving laboratory needs of donor institutions' (Lwanda, 2007). Nevertheless, such pharmaceutical developments constructed from local knowledge from Malawi and scientific knowledge from the global north amplify the superiority and power of bio-medicine.

Following this, several research projects and medical campaigns were conducted during the colonial period to prevent the spread of sleeping sickness, measles, pellagra, small pox and other diseases. A majority of these research projects and medical campaigns were led by Europeans and results were published in journals from the global north. Thus, the publications of the early colonizers largely contributed to the perception of Africa as a laboratory in which new discoveries on tropical diseases could be explored and 'a place where scientific reputations' could be made (Vaughan, 2013).

The conduct of health research was however minimal following the country's independence because research was seen as a form of exploitation by Dr Kamuzu Banda. International collaborative research programmes however begun to increase in the 1980's following the discovery of HIV/AIDS. National regulations to coordinate the conduct of the health research and minimize exploitation were therefore developed in the 1990's as it will be shown in the following paragraph.

Health research regulations in post-colonial Malawi

One of the objectives in the Health Sector Strategic Plan for Malawi is to regulate and coordinate health research. Proposed strategies to attain this objective include: capacity building for research, strengthening the governance role of Ministry of Health in the conduct of health research, resource mobilisation for research, and to promote utilization of evidence in policy formulation (Government of Malawi., 2011). While the government has managed to strengthen research governance and capacities of institutions and individuals, funding for research by the government remains low (Kirigia et al., 2015). For instance, only 0.26% of the total government budget was allocated to research for a five year period from 2011 to 2016 (Government of Malawi., 2011). As such, a majority of the medical research projects are funded by international institutions and donors such as NIH, Wellcome Trust, CDC and others.

The National Commission for Science and Technology was established in 1993 to coordinate and regulate the conduct of research. Three research ethics committees were therefore set up by the commission to review protocols and ensure that research is conducted in a scientific and ethical manner. Health research protocols from COM and affiliates are submitted to College of Medicine Research Ethics Committee (COMREC) for review to ensure that research is conducted in a scientific and ethical manner. A national health research agenda

was also developed by the Ministry of Health in 2012 to guide researchers, academic institutions and other stakeholders on relevant research priorities for Malawi and these include: HIV/AIDS, respiratory infections, malaria, diarrhoea diseases, Non Communicable Diseases, TB, and cancers (Ministry of Health., 2012).

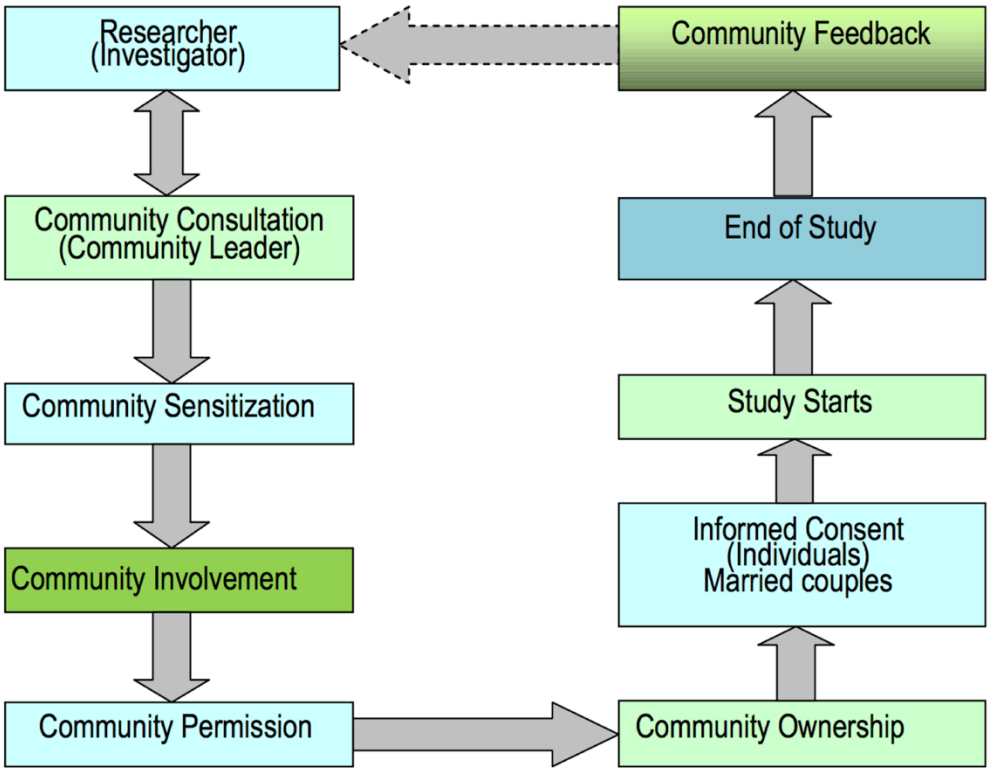
University of Malawi-College of Medicine

In 1991, a medical school (COM) was established in Blantyre to train physicians. With support from overseas academic institutions, COM hosts several research and training centres including the Malawi Liverpool Wellcome Trust Clinical Research Programme, the Malaria Alert Centre, Tropical Research Unit of Excellence, Malawi Epidemiological and Intervention Research Unit and Johns Hopkins University Project (Muula and Broadhead, 2001, Muula et al., 2016). A majority of the research projects are conducted in collaboration with the District Health Office and hence implemented at QECH, surrounding health facilities, communities as well as in other research sites such as Chikwawa, Lilongwe and Karonga. Both local and international research fellows from COM and its affiliates conduct research to generate evidence to inform policy as well as to advance knowledge. These collaborations led to an increased number of publications by 103% between 1996 and 2006, however only 21% of the publications had Malawians as first authors (Gondwe and Kavinya, 2008). Translation of research findings into practice and policy also remains a challenge (World Health Organisation., 2016b).

The Centre for Bioethics in Eastern and Southern Africa (CEBESA) was established in 2001 under the department of Community Health at COM (Mfutso-Bengo, 2014). Some of the roles of CEBESA were to train COMREC members and university students on ethics and to assist health care workers, students and policy makers to address ethical issues. In addition, CEBESA also established a Medical Rights Watch to raise awareness among community

members on their rights and responsibilities. As part of its activities, researchers from CEBESA conducted a number of research projects to understand community attitudes towards health research and to improve informed consent processes (Mfutso-Bengo et al., 2008b, Masiye et al., 2008). Outputs from the research included recommendations on community engagement (Mfutso-Bengo et al., 2008b) presented in figure 3.2. There are however no regulatory requirements to comply with these.

Figure 3.2: Recommendations for community engagement



Source: (Mfutso-Bengo et al., 2008a)

Malawi Liverpool Wellcome Trust

MLW was established in 1995 and initially focused on conducting research on malaria. At the time, this study was being conducted in 2015, MLW had expanded to cover a broad range of research topics including: HIV/AIDS, TB, malaria, Non-Communicable Diseases and

vaccines. Over 100 research projects have been implemented to date. The Science Communication department was established in 2008 to lead both programme wide and study specific engagement activities. Some of the public/community engagement activities run by the department include: CAG, science cafes, science exhibition project, radio programme and community sensitization meetings.

3.4 Study setting

The study was conducted in both an urban and rural district located in southern Malawi. Two case studies were conducted in an urban setting in Blantyre, one case study was conducted in a rural setting in Chikwawa.

3.4.1 Blantyre district

Blantyre is the second largest city in Malawi with a population of 1,001,984 (National Statistics Office., 2008). Due to urbanisation, a majority of residents in the city have migrated to Blantyre to seek employment or business opportunities. As such, residents in the city have multi ethnic backgrounds and traditional beliefs. The predominant language is however Chichewa while the official language is English.

There are several townships in Blantyre, with both low and high-density populations. A majority of the people in the city reside in high density areas depending on paid employment or small business enterprises for survival. Despite that residents in urban settings have relatively higher literacy levels and better access to infrastructures such as health facilities, most of the urban poor are faced with ill health due to poverty, poor sanitation and food insecurity. The prevalence of diseases such as malaria, diarrhoea, Tuberculosis and HIV/AIDS are therefore high particularly among the urban poor living in slums (See figure 3.3) and this makes the place appropriate for research. Research is however not the only

health care provider in the region because there are other non-governmental actors who are working to improve the well-being of people living in the area.

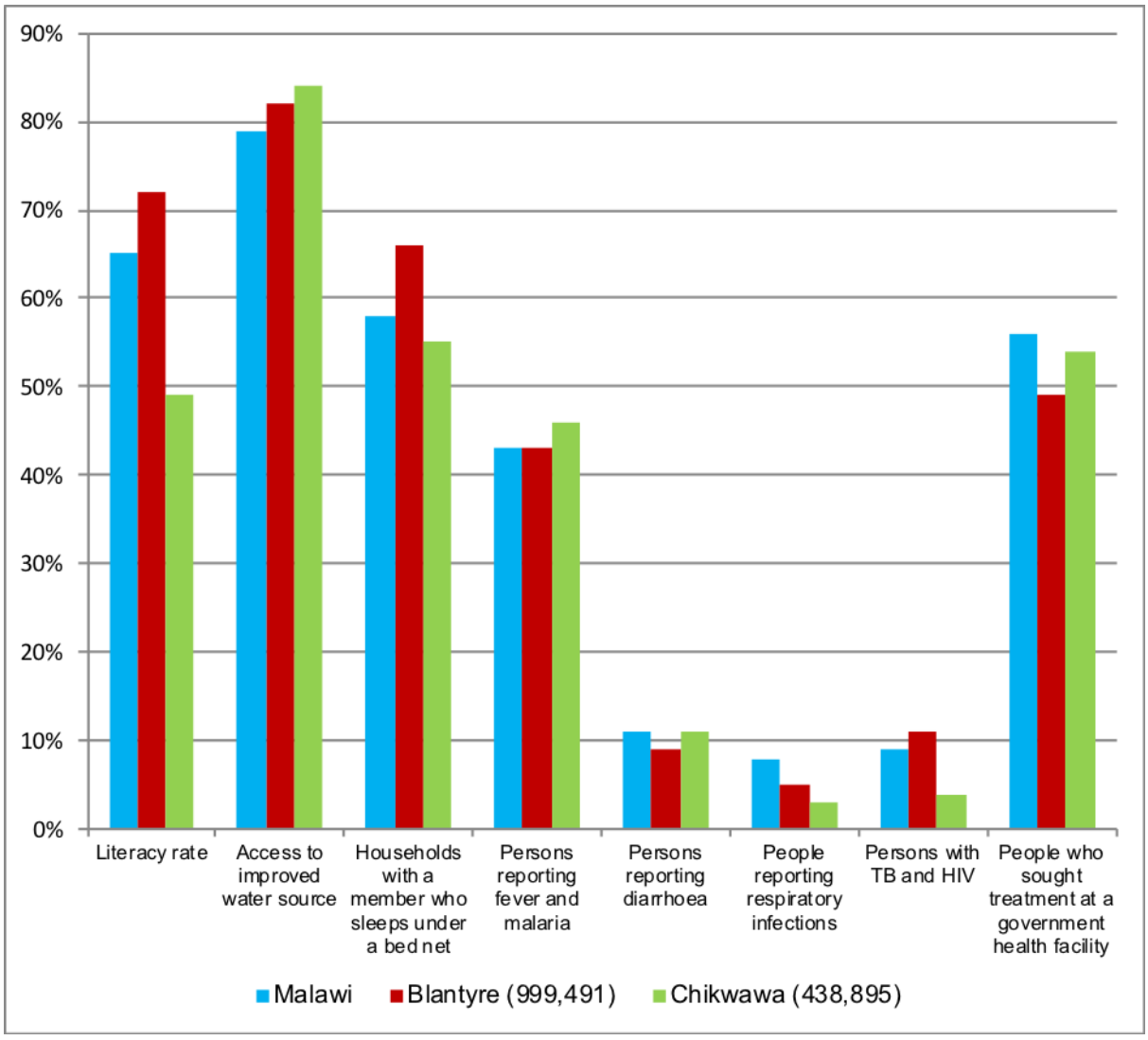
3.4.2 Chikwawa district

Chikwawa is a rural district located about 50 Kilometres south of Blantyre. The population for Chikwawa is 434,638 (National Statistics Office., 2008). There are several villages in Chikwawa headed by village headmen. Clusters of villages are grouped under the headship of a group village headman who reports to the Traditional Authority. Compared to Blantyre, most of the residents are originally from the district except for people working for the government, sugar plantation and other service providers. As such, most people particularly in remote areas share the same ethnic group, language and traditional beliefs. The predominant ethnic group in Chikwawa is Mang'anja while Chichewa, Mang'anja and Sena are the popular languages. Literacy levels are low (49%) compared to the country's average literacy rate of 65% (National Statistics Office., 2012). Most children do not complete primary education due to poverty and early marriages. As such, most of the people in Chikwawa depend on subsistence farming and small business enterprises for survival.

Chikwawa is one of the malaria endemic districts in Malawi due to its climatic conditions which are hot and humid. Despite efforts from the National Malaria Control Program to improve prevention and treatment of malaria through distribution of free Insecticide Treated Nets, indoor residual spraying and improving case management, malaria remains the leading cause of morbidity and mortality particularly among children below five years old (National Statistics Office., 2012). As such, most research projects conducted by MLW in Chikwawa focus on malaria as well as other diseases such as pneumonia and flu. Access to infrastructures such as health facilities is also challenging in most villages and this contributes to poor health outcomes. Figure 3.3 shows statistics in relation to literacy levels,

prevalence of diseases such as malaria, diarrhoea, TB and HIV/AIDS to illustrate the socio-economic context where the research was conducted.

Figure 3.3 Household socio-economic characteristics for Chikwawa and Blantyre



Source: National Statistics Office (2012), Third integrated household survey.

3.5 A description of three case studies

This study focused on three research projects as ethnographic case studies namely Pneumococcal Carriage in Vulnerable Populations in Africa (PCVPA), Majete Malaria Project (MMP) and Studying the intrapulmonary pharmacology and immunology of Tuberculosis therapy (SPITT). These case studies will be referred to as the urban case study,

rural case study and the hospital case study respectively. The urban and hospital based case studies were implemented by MLW while the rural case study was implemented by COM. In this section, I will describe the study aims, research procedures and community engagement approaches used in all the three research projects.

3.5.1 The urban case study: PCVPA study

PCVPA is a four-year study implemented in Blantyre by MLW. The study aims to assess the impact of introducing Pneumococcal Conjugate Vaccines (PCV) on herd immunity in children and adults. Pneumococcal Conjugate Vaccine (PCV 13) was introduced in November 2011 as a routine childhood vaccine to prevent pneumonia, meningitis and other diseases. The study recruited children between the ages of two and four who were vaccinated after the Ministry of Health introduced PCV in 2012, school going children between the ages of six and ten who were not vaccinated and adults taking Anti-Retroviral Therapy (ART) from Queen Elizabeth Central Hospital (QECH). These three groups were selected in order to find out how PCV 13 was protecting children who received the vaccination as well as older children and adults who did not receive the vaccine. The study involves taking nasal swabs from children and ART clients in two cross-sectional surveys per year over the four years.

Community engagement activities

There was a sequence of community engagement meetings initiated by the study team that took place prior to study implementation. The study team held meetings with officials from the District Education Office, members of Parents and Teachers Association committees (PTA), parents and guardians as well as children. The aims of the community engagement meetings were to ensure that all stakeholders were informed about the study and that study recruitment was taking place in a transparent manner and well understood by stakeholders.

These community engagement activities were developed and led by the study team and community engagement staff who were not part of the project.

Meeting with senior education officials

The first meeting was held with senior education officials from the District Education Office as well as Primary Education Advisors (PEA). This meeting took place in a school hall at a primary school in Blantyre. A total of 13 officers from the District Education Office (four women and seven men) attended the meeting in addition to five research staff (two women and three men). The research team included the Principle Investigator, the Study Coordinator who were both non-Malawians, two research nurses and a community engagement fieldworker.

The meeting started with a prayer by one of the attendees. Thereafter, the community engagement officer explained the rationale for the meeting which was to strengthen relationships with Primary Education Advisors and to seek feedback on the research project. Initially, most of the attendees indicated challenges to understand the rationale and aims of the research. Having a small group discussion after the presentation allowed the attendees to seek clarity on issues that they did not understand.

Some of the issues that were discussed further included how researchers planned to approach each school and who will be involved in the drama. Through the discussions, the PEA gave recommendations that meetings should be held with parents so that they understand the research objectives. The PEAs also recommended that the researchers should include school management committees and that a PEA should accompany the research team at the meetings with PTA committees.

Meetings with Primary Teacher Association committees (PTA)

Thereafter a series of meetings were held with Primary Teacher Association (PTA) committees from all the seven participating primary schools. A total of 15 to 40 PTA members attended the meetings which took place at each school. The two research nurses communicated the research project using both Chichewa and English. The floor was open to attendees to ask questions, seek clarity, voice their opinions and staff from MLW took turns to respond to questions. Both the research nurses and the community engagement officer responded to study related questions and the recruitment strategy.

Meetings with parents

Following the PTA meetings, three out of the seven schools suggested that additional meetings should be held with parents and guardians for the children to inform them about the study. The main rationale for having the meetings was that participation will improve if parents are informed about the study. Thus, letters were only sent with the children at the three schools to invite parents to a meeting. The format of this meeting was similar to the PTA committee meetings and attendees were also given the opportunity to ask questions or seek clarity on issues. A total of 150 to 300 parents attended each meeting which lasted for about two hours.

Meetings with students

Finally, community engagement meetings were held with students in all the schools. These meetings began with music followed by a drama performance by a popular theatre group to communicate the study objectives. The plot of the drama was similar in all the schools and lasted between 10 and 20 minutes. The drama was followed by a quiz where the research nurse asked questions about the research project and students who gave correct responses

received prizes. More than 500 students aged between 6 and 10 years old attended the students' engagement meetings which were mostly held outdoors (See figure 3.4). Having a large number of students made it challenging for some of the students to understand key messages. This was evident during quiz time because some students regardless of age were unable to give correct responses.

Figure 3.4: Pictures of community engagement activities

Study recruitment

Thereafter the research staff randomly selected 45 students at each school. These students were given study information sheets which were written in the vernacular language. The student was expected to hand the letter to their parent or guardian to indicate whether they were willing to let the child participate in the research. Parents who were willing to participate in the study were expected to write the date and time that they would go to the school to give a written consent for the child to participate. Recruitment of research participants took place in each school. The research nurse explained the details of the study and obtained consent from parents and an assent from the child. Thereafter the field worker asked a number of questions concerning the child's history of vaccination, socio demographic

details and household possessions. The research nurse finally took a nasal swab and the research participants were given sweets, a drink, notebooks and MK1, 000 (USD1.25) as transport reimbursement.

I purposively selected two school communities to be the main focus of the study in order to have an in-depth understanding of how different school communities responded to the same research project. Ndirande and South Lunzu school communities were therefore selected because of their location and previous exposure to research. Ndirande is located in Blantyre city and the school community has been involved in numerous research projects conducted by COM as well as other organisations. On the other hand, South Lunzu is located in peri-urban Blantyre and the school community has been exposed to fewer research projects.

A comparison of Ndirande and South Lunzu

Ndirande and South Lunzu are densely populated locations in Blantyre. Most of the houses were small, closely spaced and roofed with dilapidated iron sheets. Some of the houses were semi-detached while other houses had fences around them. There were no road networks in some parts of Ndirande compared to South Lunzu and people walked in footpaths between houses or fences. Most of the dusty roads and foot paths were littered with plastic bags, sugarcane peels and other waste materials. Refuse disposal was a challenge particularly in Ndirande and the rivers were heavily polluted with rubbish. It was also common to find broken sewage systems along the footpaths while other sewage was being dispensed into the river. One could therefore smell the stench of urine or sewage along some of the footpaths in Ndirande. Nevertheless, there were a number of Non-Governmental Organisations and research institutions such as Red Cross, Johns Hopkins, Blantyre Malaria Project and MLW implementing health related projects in Ndirande compared to South Lunzu. Socio-

demographic details of the two communities have been provided in table 3.1 below to show the contrast in the population density between the urban and peri-urban setting.

Table 3.1: Details of Ndirande and South Lunzu

	Ndirande	South Lunzu
Total number of household members	109,191	54,503
• **No. of men**	34,962	17,172
• **No. of women**	31,779	17,387

Source: MLW HIT TB Study data, 2016.

3.5.2 The rural case study: MMP study

MMP is a five-year cluster randomised trial aimed at reducing the incidence and prevalence of malaria in the rural district of Chikwawa. The project was implemented by University of Malawi-College of Medicine alongside both local and international partners namely: Liverpool School of Tropical Medicine, Wageningen University, National Malaria Control Programme, The Hunger Project and African Parks-Majete. The study was implemented in 71 villages that were divided into three focal areas A, B and C surrounding Majete Wildlife Reserve (MWR). Throughout this thesis, the three focal areas will be referred to as focal area X, Y and Z respectively. There were four interventions in the study that required community participation: house improvement (HI), larval source management (LSM) and roll back malaria (RBM) techniques such as mass coverage of Insecticide-treated bed nets (ITN) in addition to diagnosis and treatment for malaria.

As part of the community engagement strategy for MMP, communities were asked to select volunteers from participating villages to serve as health animators. Each village also selected committee members to assist in the implementation of interventions such as house improvement and larval source management. A curriculum was developed by the researchers to train the health animators on various interventions that were implemented. The health animators organised weekly village workshops to train other community members on malaria prevention and to mobilise communities to implement interventions. Participatory evaluation with the health animators was used to monitor the impact of the intervention.

House improvement was an intervention where villagers were encouraged to cover openings in their houses particularly between the walls and the roof and they were also given iron mesh to cover windows to prevent mosquitoes from entering the houses. Most of the houses in the villages were thatched with grass or iron sheets and the eaves were usually left open especially for the grass thatched houses. The committee members enumerated the houses in the village that had open eaves. With support from village heads, the villagers were encouraged to cover the eaves by using mud and bricks. The committee members also took measurements of the windows/openings that required iron mesh and each household was given iron mesh. At the time when I was collecting data, most of the houses had already been covered with the iron mesh by household members.

Larval Source Management was the management of breeding sites for mosquitoes to reduce the population of mosquito larvae by draining, filling or applying chemicals to water bodies. Health animators were trained by the research staff to map breeding sites for mosquitoes and mobilise the communities to drain or fill the breeding sites. Later on, the health animators were also trained by the research staff to apply *Bacillus Thuriengensis Israelensis* (BTI) to

kill mosquito larvae in large breeding sites that could not easily be drained or filled. BTI was however not locally available and the researchers had to import it from other countries.

Every household was given insecticide treated bed nets (ITNs) to prevent them from mosquito bites. Distribution of the ITNs was done in collaboration with the Ministry of Health National Malaria Control Programme. Community based health care workers had collected data on number of households in each village, number of individuals per household and number of sleeping places per house. Each household was therefore given bed nets in accordance to the number of sleeping places in the house. There were however delays in the distribution of bed nets because the villagers received the ITNs after the rainy season in May, 2016. Delays in the distribution of bed nets led to resentment among most of the community members. Despite being given iron mesh for the windows, most of the community members expressed concerns that the researchers had delayed to give them the bed nets.

In order to assess the effectiveness of the interventions to reduce incidence of malaria, households with children below the age of five years old were randomly selected for rapid malaria tests. Field workers informed community leaders and the selected households about the date for the malaria tests. The research nurses therefore conducted rapid malaria tests and provided treatment for children found with malaria. In addition to the interventions described above, there were other research projects nested within MMP study focusing on entomology, behaviour change and epidemiology.

Out of the 71 villages that were participating in the research project, I decided to select four villages in consultation with research staff. I therefore selected Kabwatika and Zabuka in focal area X and Liwonde and Kandeu in focal area Y. These villages were implementing all the interventions. Focal areas X and Z had an epicentre run by the Hunger Project that focused on clusters of villages (focal areas) to provide programmes in health, education,

nutrition, improved farming and food security, microfinance, water and sanitation. An epicentre included a building with a health facility, microcredit bank, food bank, lecture room and a library. I will explain the reasons for selecting these sites in chapter four.

All the four villages had limited access to electricity, piped water, mobile network and other infrastructures such as secondary schools, health facilities and public transport. The road infrastructures were poor with limited public transport services. Most of the people walked on foot or used bicycles to access essential services. Secondary schools were also located further away from the villages and most of the children dropped out of school due to poverty and long walking distances. Consequently, literacy levels were very low in all these settings. A majority of residents lived in grass thatched houses and they depended on selling farm produce or charcoal for survival. At the time when this research was being conducted in 2015/16, most parts in Chikwawa were either affected by floods or dry spells. As such, food production was very low and most of the families were food insecure.

Table 3.2: Details of the villages from Chikwawa

	Kabwatika	Zabuka	Liwonde	Kandeu 1
Total number of households	57	61	170	198
• **No. of men**	17	35	97	94
• **No. of women**	40	26	73	104

3.5.3 The hospital-based case study: SPITT study

SPITT was an invasive case control study aimed at understanding functions of immune cells as well as effectiveness of TB medication in the lungs of patients taking TB medication. The lead Principle Investigator (PI) for the study was a PhD student from LSTM based at MLW

alongside collaborators from QECH, COM, LSTM and UoL. The research team included three people: the PI, a research nurse and a clinical officer who were housed at QECH.

The research team recruited people diagnosed with TB from QECH and two other primary health facilities namely Limbe and Ndirande health facilities. As such, research participants did not come from a specific geographical location. After a patient consented to participate in the research, an initial visit at the hospital involved taking patients medical history, a chest X-ray, HIV test and blood samples in order to assess the functions of the liver and kidney. Following this, a patient was asked to provide sputum samples to the research team every fortnight over a period of eight weeks. Thereafter, bronchoscopy tests were taken at the eighth and the fifteenth week at the clinical investigation unit at QECH. The tests required individuals not to take anything in the morning except for the drugs. Blood samples were thereafter taken every two hours to test drug levels in the blood. In between the blood tests, the patient lay on a trolley where the throat was numbed with an anaesthetic spray, thereafter a bronchoscope was inserted through the mouth into an air tube to suck fluids in the lungs. The fluids were later sent to the laboratory and the whole procedure required one to spend almost the whole day at the clinic. Thereafter, patients were followed up after two to three days to ensure that there were no side effects from the research procedure. They were then asked to return to the hospital after six and 12 months of treatment for a short assessment. In between the 12 months they were contacted by telephone for follow ups. Instead of the bronchoscopy, other patients were asked to provide two blood samples of five millilitres to measure drug levels in addition to a breath sample.

Prior to this study, formative qualitative work involving FGDs were used as part of the community engagement activities. The FGDs were conducted with adult patients with pulmonary TB and other community members in urban Blantyre. The aims of the FGD were to explore TB patients and community members understanding of study information on

bronchoscopy-based research and to seek their feedback on the research. During the FGD, participants were provided with information sheets for the study in the local language. Information about the proposed research on SPITT was explained to them in the local language, and they were given the opportunity to ask questions. The FGD covered issues of understanding of research, motivation for participation in studies of this nature, concerns, and feedback on the information provided to participants. Feedback from the FGD was then used to inform the design and development of study information sheets.

3.6 Conclusion

In conclusion, I have given a description of the contexts where each research project was taking place. My focus has been on the history, politics, socio-economics as well as health service delivery and health research. I have also given a description of the three research projects and the community engagement activities in the studies.

The detailed contextual background in this chapter is relevant to understand how different communities responded to the research projects, the underlying factors in the contexts that influenced them to engage with researchers and factors that contributed to negative or positive engagement experiences. In chapter four, I will provide a description of the research methodology of this study.

Chapter 4: Research design and methodology

4.1 Introduction

This research aims to understand the purpose, relevance and benefits of community engagement in health research. I used a qualitative research design to gain in-depth understanding of community engagement as experienced by different people involved in research such as researchers, field workers, Community Advisory Groups (CAG), research participants, non-research participants, community volunteers and other research staff.

Three research projects were selected as ethnographic case studies. Ethnographic case studies were used to understand the explicit and tacit aspects of community engagement in health research (DeWalt kathleen., 2002). I also used a number of data collection techniques such as participatory workshops, participant observation, interviews and focus group discussions (FGD) to triangulate findings and enhance data validity.

Preliminary formative work was done by conducting two participatory workshops with existing CAG members to understand their advisory roles in research and to seek feedback on the proposal. Thereafter, I observed and participated in community engagement activities, daily activities and interactions between researchers, community volunteers and community members. Forty-three Semi Structured Interviews (SSI) and 17 FGDs were used to understand local people's emic interpretations of their experiences. Preliminary findings were fed back to research teams and research participants for discussions and feedback.

Since most of the research projects were running for more than three years, I decided to focus on three months of their implementation because I had 12 months for data collection and analysis. In this chapter, I will discuss the study design (4.2), selection of ethnographic case studies (4.3), data collection processes (4.4), data analysis (4.5), respondent validation (4.6), reflexivity (4.7), and ethical considerations (4.8).

4.2 Study design

A qualitative research design was most suitable for answering the research questions because it provides in depth evidence of experiences from local peoples perspectives (Smith P & Morrow R., 1996). Since community engagement involves interactions between multiple stakeholders in a given context, qualitative research was well suited to explore complex issues that require an understanding of the social phenomena in a given context (Ritchie and Lewis, 2003). By using a qualitative study design, I expected to understand how interactions between researchers, field workers and research participants shape community engagement practice and knowledge production. A qualitative research design was also ideal to enable me to understand the contextual factors in urban and rural settings that shape community's response to research and to draw overarching interpretations of engagement practices across different research settings.

One of the approaches used to research complex issues is the use of case studies. Case study research is a type of qualitative approach that explores a case or multiple cases over time, through in-depth data collection involving multiple sources of information (Merriam and Tisdell, 2015). I decided to employ an ethnographic case study approach to observe and participate in daily interactions involving researchers, research participants and other community members. According to Bernard (1994, p.138), ethnographic research can involve two roles of participating observer and observing participant. I assumed roles of complete observer during community engagement events and observer as participant during my stay at the field sites. I expected to build rapport with research communities to understand unarticulated aspects of community engagement in health research. Through participant observation, I documented descriptive field notes about my etic perspectives. These insights were further explored during FGD and SSI to triangulate findings.

4.3 Selection of ethnographic case studies

I selected three research projects as ethnographic case studies from various research institutions in Malawi to explore the differences in community's response to research. I will use the term research project to describe the trials that the engagement activity was attached to and use the term ethnographic study to describe my research. The ethnographic case studies focused on study specific community engagement strategies in rural, urban and hospital settings to compare how communities responded to the research projects in these different settings. Two community based research projects and one hospital based research project from University of Malawi College of Medicine (COM) and MLW were therefore selected.

I presented my proposal to Directors from three research institutions that are affiliated to COM for formal research approval. Thereafter I was directed to programme leaders responsible for community engagement. The programme leaders from two research institutions indicated that they did not have new research projects with community engagement at that time. Only the contact person from MLW provided a list of studies that were expected to start in 2015 and 2016. I met with a community engagement officer from MLW and we reviewed the list of studies with an aim of selecting research projects. Details of the selection process and reasons for exclusion have been provided in Figure 4.1. Purposive sampling was used to select information-rich cases (Patton, 2002) to provide in-depth understanding of how communities were engaged in health research. Out of the 56 research projects at MLW, only one community-based research project in an urban setting was selected because it met my selection criterion. The second case study was identified through contacts with group leaders and this was a community-based research project in a rural setting at COM. I selected two research projects in an urban and a rural setting to

compare and contrast how communities in both settings with diverse socio-economic characteristics responded to research. The third hospital-based research project was identified through a PhD student at MLW. Details of the research projects have been included in Table 4.1. During the course of data collection, I tried to identify a fourth case study. I had challenges however to allocate my time to travel to Chikwawa for data collection, code the transcripts and focus on the hospital-based case study. In addition, there were some delays in the rural case study and this prolonged my data collection. As such, I decided to focus on three case studies.

Since I could not conduct ethnography in all the 77 geographical locations that were being targeted by the community-based research projects, I purposively selected two sites in the urban setting and two sites in the rural setting to be my main focus. Maximum variation sampling techniques were used to select the urban and rural sites because it allows one to identify common or diverse patterns that cut across heterogeneous cases (Patton, 2002). In the urban case study, I engaged the research team and science communication staff to discuss the communities where participation in research was challenging and communities where participation was less challenging. I therefore selected Ndirande and South Lunzu because recruitment of study participants was much easier in Ndirande compared to South Lunzu. I followed a similar process in the rural case study and four intervention villages were selected. I selected Kabwatika and Zabuka villages in focal area X, and Liwonde and Kandeu villages in focal area Y because research staff had observed that community participation in focal area X was better compared to focal area Y. Kabwatika and Zabuka were small villages very close to each other while Liwonde and Kandeu were also next to each other and they were randomly selected by the study team to implement all the interventions. By having a small sample of great diversity, I expected what Patton (2002, p. 235) calls *'high quality, detailed*

description of each case, useful for documenting uniqueness and common themes emerging from the cases'. In this case, I was interested in exploring contextual factors that affect study acceptability as well as other factors that affect community engagement. By comparing experiences from the three case studies across the different settings, I was hoping to find common themes in relation to community involvement in research as well as unique themes for each setting.

The limitation with this approach is that data collection took place within a specific time frame and not throughout trial implementation. Since ethnography requires lengthy immersion in the daily lives of study participants (DeWalt kathleen., 2002), this study may not be able to explain the changes in community response over a long period of time since people's views of research are likely to change over a period of time. The focus of this ethnographic study was on study entry and implementation and to explore community engagement in multiple case studies. As such, community engagement after study implementation or sustainability of behaviour change has not been taken into consideration.

Figure 4.1 Selection of case studies

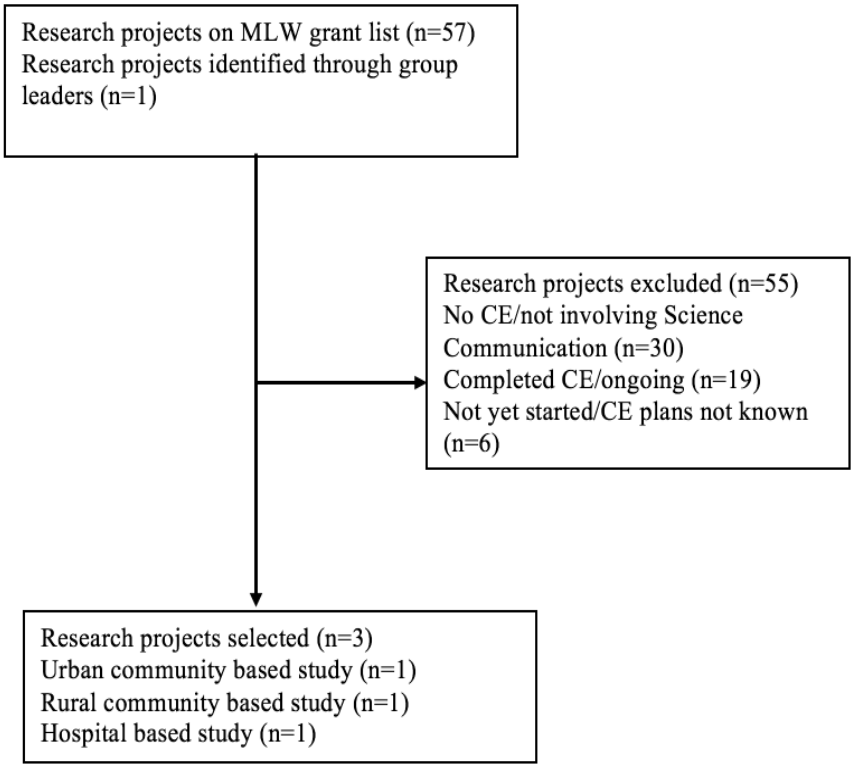


Figure 4.2: Selection of sites in community-based studies

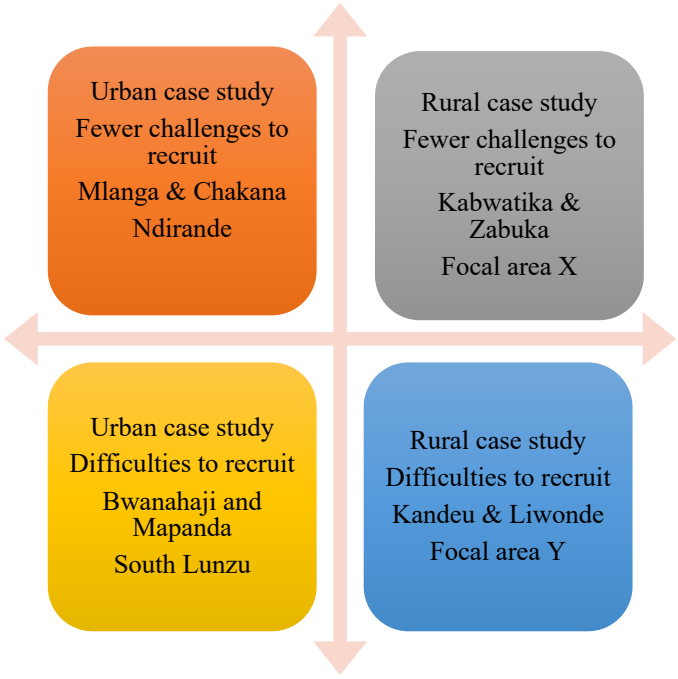


Table 4.1: Details of the case studies

	Urban case study	Rural case study	Hospital case study
Implementing institution	MLW	COM	MLW
Study design	Observation study- 4 cross sectional surveys per year	Intervention study- Cluster Randomised Trial	Case control
Study duration	4 years	5 years	2 years
Setting	Blantyre, urban setting	Chikwawa, rural setting	QECH, Blantyre
Study aims	Assess the impact of introducing PCV on herd immunity	Implement interventions to reduce the incidence of malaria	Assess how TB drugs and the immune system function to cure TB
Target population	7 school communities 30 children per school	77 villages Every household in selected villages	TB patients referred to QECH
Research activities	Nasal swabs Personal information	Closing eaves, covering windows with iron mesh, using insecticide treated nets, LSM, malaria testing, entomology	Clinical assessments HIV testing Blood tests Chest X-ray Breath tests Bronchoscopy
Aims of CE	Raise awareness about the study To get feedback on the research and engage in two-way dialogue with communities	To educate and empower communities to implement interventions aimed at preventing malaria	To explore TB patients and community members' understanding of study information on bronchoscopy-based research and to seek their feedback
CE activities	Meetings with Primary Education Advisors (PEA) Meetings with Parents and Teacher Association committees (PTA) Meetings with parents Meetings with students Study information sent to communities	Community involvement to select volunteers and committees Training of Health Animators Village workshops facilitated by health Animators Health Animators involved in monitoring and evaluation	Consultation FGD Sensitization of health care workers

4.4 Data collection approaches

This study employed multiple data collection methods such as participatory workshops, participant observation, unstructured interviews, SSI and FGD. I initially conducted two participatory workshops with CAG members from Blantyre and Chikwawa to seek feedback on the research and to understand their roles in research. Thereafter, I observed and participated in daily activities of researchers, field workers, CAG members, research participants and other community members in the urban case study. Field notes were documented during participant observation and some of the issues observed were further explored in SSI and FGD. A similar sequence of data collection approaches was followed in the rural and hospital based case studies. Data collection and analysis was ongoing and iterative. Main themes that were noted in the urban case study were further explored in the rural and hospital based case studies to compare findings from the three case studies. Preliminary findings were discussed with study teams and communities for participant checking. In this section, I will describe the data collection processes in all case studies. Figure 4.3 and table 4.2 provide an illustration of the data collection process.

Figure 4.3: Data collection processes

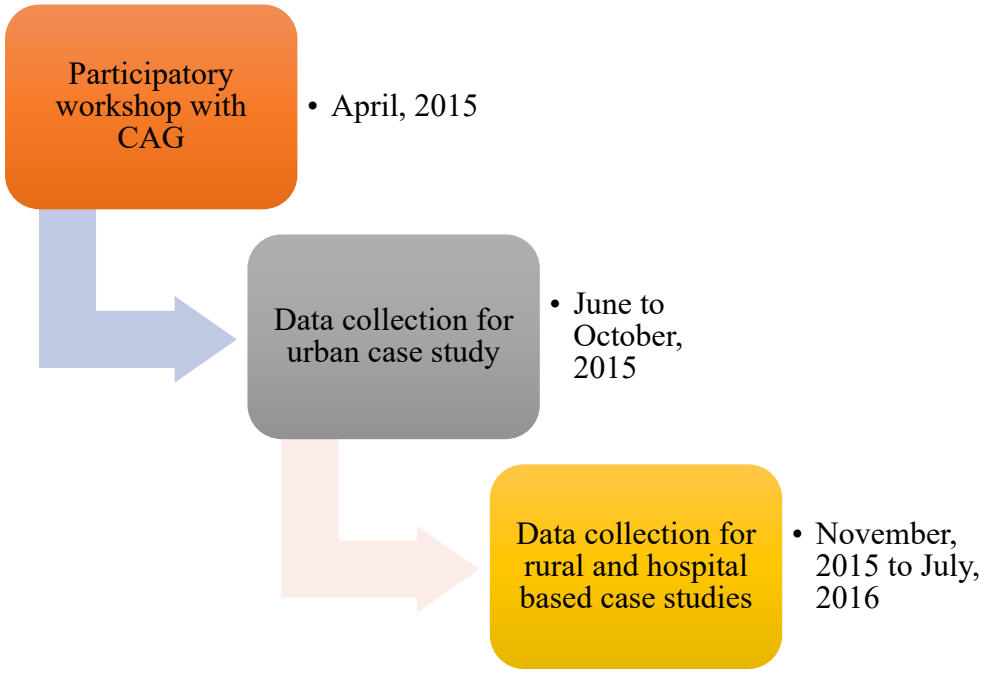


Table 4.2: Data collection methods

	Urban case study	Rural case study	Hospital case study	Total
Participatory workshops with CAG*	✓	✓	✓	
Document reviews of minutes for meetings with CAG, CE documents	✓	✓	✓	
Participant Observation	✓	✓	✓	
Unstructured interviews with research stakeholders	✓	✓	✓	
Semi structured interviews				
• Research participants	9	7	4	20
• Community leaders	3	3	N/A	6
• CAG members/Health animators	3	4	N/A	7
• Study team members	6	2	2	10
Focus Group Discussions	7	8	2	17

* The CAG members in the urban case study were MLW CAG but not involved in the research project. In the rural case study, they were not residents in sites where research was conducted because they were MLW CAG.

4.4.1 Formative work: Participatory workshops with Community Advisory Groups

A Community Advisory Board (CAB) or Community Advisory Group (CAG) is a group of community representatives who provide community oversight on ethical conduct of health research (Boulanger, 2013). Roles of CAG include reviewing study protocols and informed consent forms, representing community concerns, advocating for the rights of research participants, consulting with potential research participants to provide advice, identifying research priorities, assisting in development of study materials, study design and implementation (Quinn, 2004, Strauss et al., 2001, Newman et al., 2011, Morin et al., 2003).

The CAG at MLW were set up in 2009 to represent the community's perspective on health research. There were however, no clear guidelines to determine the types of studies needing to engage a CAG. The decision to engage a CAG in a research project was therefore left optional to researchers. Two institutional CAG were established in the urban and rural district. The CAG members were volunteers who resided in geographical locations where MLW was implementing research; twenty-six members were selected from six townships in the urban district and 48 members were selected from 39 villages in the rural district. CAG members from urban areas were selected from geographical locations surrounding health facilities where various research projects were being implemented. For rural areas, CAG members were selected from geographical locations where a community-based intervention was being implemented.

A manual was developed by science communication staff and it was used to guide selection, operation and training of CAG. CAG members were trained by science communication staff on the following topics: MLW's vision, functions of CAG, clinical research, protection of research participants, leadership skills and report writing. MLW organized quarterly meetings for CAG members and science communication team, where they presented their reports and discussed new research projects as well as other ongoing research projects. The CAG

members were involved in this doctoral research, but they were not engaged in all the three case studies.

I conducted two participatory workshops with CAG members from two districts (Blantyre and Chikwawa) where MLW is implementing research projects. Participatory workshops are used to engage communities to decide the research agenda or to have a voice on research that concerns their lives (Northway et al., 2014). The aims of these workshops were to use existing community engagement structures to engage CAG members to give feedback on my research and understand their roles in research more generally. Workshop participants were purposively selected from a list of CAG members based on gender and location. A total of 37 CAG members (21 males and 16 females) attended both workshops (See appendix two). There were more men compared to women in the CAG, as such more men attended the meeting. Consent was sought from workshop participants to record workshop proceedings. I facilitated both workshops alongside a research assistant and each workshop lasted for about six hours. Plenary sessions, group discussions and individual responses on sticky notes were used to understand their roles in research and solicit their feedback on this research.

Workshop participants were asked to fill a registration form and a summary of the socio demographic details has been provided in appendix two. At the beginning of the workshop, I presented the research proposal to workshop participants using power point presentation and participants were given an opportunity to ask questions about the study. Workshop participants were then divided into three to four groups and asked to give any general views about the study and suggestions for improvement. Group leaders presented the responses to the whole group in a plenary session and a summary of the feedback was documented. Thereafter, study information sheets were handed out to each participant for review. Participants were asked to form groups again and write down their feedback on a flip chart. Group feedback was again discussed in a plenary and later on used to amend the study

information sheets. Towards the end of the workshop, I facilitated an open discussion on how they work with researchers, community and asked them to share experiences of how they execute their responsibilities in research.

Following this, I carried out document reviews of past CAG meeting reports in order to understand concerns raised by the CAG members. Findings were presented to science communication staff, CAG members and published elsewhere (See appendix 11). Main themes from the workshops and discussions with science communication staff and CAG members were further explored in subsequent data collection to broaden my understanding of roles of CAG members.

Figure 4.4: Pictures from the workshop with CAG members

4.4.2 Ethnographic fieldwork/participant observation

Participant observation was used to understand both explicit and unarticulated aspects of community engagement in health research. Participant observation involves establishing rapport with a social group in their natural setting and studying their daily interactions and activities through observing and participating in their activities (Kawulich, 2005, Zaharlic Amy, 2005, Reeves et al., 2008). I participated in daily activities of researchers, community engagement staff, field workers and community members. I spent a period of three months in the sites where research was being conducted to become familiar with the context, experience

how communities were being involved in research and observe how they implemented health interventions. I also observed daily interactions between community engagement staff, field workers and community members during meetings. By conducting an ethnography, I was able to understand the context where research participants reside, experience some of the issues that affect them in their daily lives and to understand their views on community engagement. Through the ethnographic field work, I was also able to identify themes that informed the topic guides used in SSI and FGD to get detailed views about each theme.

My initial plan was to identify local hosts to live with during field work, I however experienced some challenges. In the urban case study, I initially went to the head teacher at South Lunzu primary school where I presented written documents about my study. I asked the head teacher if she could help identify a family whose child has been invited to take part in the research to become a local host. The head teacher responded that the teachers were not involved in selecting the children but promised to consult other teachers to assist in identifying a suitable family. Later, she indicated challenges to identify a local host because she did not know the parents of the 15 children. The other difficulty was that they could not be certain whether the parents would be willing to let their child participate in PCVPA research project and that they could be suspicious about my intentions to live with them. I therefore went to the primary school during the recruitment period to make contacts with parents who went for enrolment in PCVPA study. While I was at the school, I met several parents and talked to them about my study.

Taking into consideration the challenges to identify a local host in South Lunzu and the limited time for field work, I decided to change my approach. I resorted to find a small house to rent prior to field work and identify a resident to become my research assistant. I therefore consulted a village head in Ndirande to help me identify a house and a lady to act as my local guide. The assistant to the village head identified Caroline who was a 31-year-old lady with

two children attending the primary school where research was taking place. Having a local research assistant proved useful because her familiarity with the context and the people allowed me to interact with various people as well as parents of children who participated in the research. With Caroline's assistance, I was able to engage in discussions with community members concerning their views on research.

This approach however only worked in the urban setting in Ndirande because there were houses available to rent. Community members in the rural case study indicated that there were no houses available for rent in the villages. They also expressed fears about my security if I were to live alone in the village. Partly, the villagers expressed fears about my security because there were many stories in the media about killings of people with albinism to sell their body parts for ritual practices. They thought that I could also be targeted because I am light in complexion compared to most Malawians. I therefore ended up staying with field workers from The Hunger Project in a nearby village called *Chibwaliso* and walked to the research sites. By staying with the field workers, I could understand field workers experiences of working in surrounding communities. The challenge however was that it may have impacted on community's perceptions of me as one of the NGO employees and hence affected the richness of data.

Community engagement experiences from the urban case study

My ethnographic experiences of community engagement in health research were varied across the three research projects. The urban case study involved collaboration with stakeholders and individual participation in research, the rural case study required community participation in the interventions while the hospital case study involved consultation FGD prior to study implementation.

During my fieldwork in the urban case study, I attended several community engagement meetings with stakeholders such as Primary Education Advisors (PEA), Primary Teacher Association Committees (PTA), parents and students. The meetings were organised by the research team and community engagement staff. I attended these meetings to observe the discussions between researchers and communities and understand how knowledge was co-produced through the interactions. My observations focused on physical environment, where participants were seated, interactions between participants, non-verbal communication, concerns with research, decision making processes within the meetings and how feedback was used by the research team. During these meetings, I was introduced as a student researcher from COM who was interested in learning about community engagement. I therefore observed the discussions while jotting down notes in a small note book. The notes were later expounded in my diary in the evenings. A list of issues that needed detailed understanding was documented and explored in subsequent conversations with informants to broaden my understanding of the issues.

In addition to attending meetings, I had initially planned to spend time with CAG members to observe and participate in their daily activities to understand how they work with communities and researchers. The CAG members however indicated that they were not actively involved in the case study or other research projects at MLW. Instead, I spent time at the research sites to become familiar with the social context, experience issues that affect them and explore community views of engagement with researchers, field workers and CAG members. I talked to people who were involved in other research projects to share their experiences of taking part in research and their views on research work. I also visited the schools where recruitment for PCVPA was taking place and I had interviews with some parents to explore their understanding of the research project, reasons for refusing or accepting to enrol in research. I followed up regularly some of the parents who had consented

to be visited in their homes to find out more about their experiences after participating in the research. Field notes were also documented after observations and conversations with different people.

Community engagement experiences from rural case study

Since the two case studies were different in terms of study design, research procedures and settings, I slightly changed my ethnographic field work approach in the rural case study. In order to have an overview of the research project, I initially had a meeting with the study coordinator who explained the various interventions that were being implemented and progress made. I also visited some of the villages that were not included in this ethnographic study to understand the interventions that were being implemented. Through this trip, I was able to understand the context and the study design which helped me plan my field work accordingly.

I attended a three days training workshop on LSM with health animators. During the training, I was introduced as a student researcher attached to COM interested in learning how researchers and health animators were engaging with communities. The training manual covered topics of: breeding of malaria mosquitoes, collecting mosquito larvae, filling and draining of breeding sites and killing mosquito larvae with BTI. Training sessions were in vernacular and participatory approaches such as group discussions and practicals were used to deliver the training. I attended this training as an observing participant to understand LSM intervention and what the health animators were required to do in the community.

Thereafter, I visited the four villages regularly for six months because activities were taking place almost concurrently. I attended village workshops on LSM that were being facilitated by health animators. In addition, I also went with villagers to identify stagnant water bodies and I assisted to cover or drain some of the water bodies. During the meetings, women sat on

the mats or the ground while the rest of the men sat on chairs. I would also sit on the ground with the rest of the women. Since most of the villages did not have adequate chairs for everyone, chairs were only reserved for community leaders, men and important delegates as a sign of respect. This reflected power relations between men and women; with men being considered as powerful and women as less powerful.

Figure 4.5: Community engagement pictures from the rural case study

Since the population density in the rural case study was smaller compared to the urban case study, I became familiar with most of the residents and the context. I visited households that were not participating in LSM to make sure that their views on the interventions were not excluded. For instance, some men from one village had told me that members of United Pentecostal Church were refusing to participate in the interventions. I visited the church leader at his house to understand his views on the interventions. At first, he appeared nervous about my visit and he was avoiding the discussions on research. Later on, he invited me to his house to meet some of his members and we discussed why they were not participating in the research.

The discussions with the pastors yielded useful insights on how religion influences community engagement with health interventions as well as ethical challenges around community-based health interventions. The church members cited verses from the Bible that state that diseases are a consequence of disobedience to God. As such, they believed that

obedience to God was going to bring blessings such as good health to their families rather than engaging in interventions aimed to reduce malaria. They also expressed their concerns with biomedicine and highlighted examples of failed health promotion initiatives such as the promotion of condoms to reduce HIV/AIDS prevalence. The church members also felt that their rights were being violated by being threatened by the village heads that they will be thrown out of the village if they did not engage with the interventions. These concerns challenged me to reflect on ethical issues in community based interventions particularly around conflicts between individual autonomy and common good. While participation in research is voluntary, some people's refusal to participate in the interventions could potentially lead to poor research outcomes. This could eventually affect the adoption of effective interventions that may benefit many people. On the other hand, this experience also made me realise that care needs to be taken when generalising study results concerning interventions that require community participation. An intervention may prove effective in a given context because a majority of community members are willing to participate.

Through the community meetings, I also learned how messages concerning research projects were relayed to community which potentially impact on community's understanding of health research. In one of the village workshops, a community based health worker explained that MLW was going to introduce flu vaccine for women and children in the village. He went further to encourage parents to send their children for the vaccination without emphasizing that it was research and that participation was voluntary. This experience led me to reflect on the suitability of communication approaches used in this particular setting and informed consent processes.

Community engagement experiences in the hospital case study

The third case study was a hospital based research project with minimal community engagement activities. Prior to study implementation, the PI for the research project approached me to help facilitate a consultation FGD. Details about the FGD have been presented in section 4.3 and published elsewhere (See appendix 12). Findings from the FGD had shown that participants had mixed views in relation to research on bronchoscopy. Some participants felt that they would participate in the research for altruistic reasons to advance knowledge while others felt that research is exploitative because research participants did not benefit from it (McCallum et al., 2016). Similarly, to other case studies, we also observed that participants had challenges to differentiate between research and a health intervention. Their motivation to participate in research was framed around the need to benefit from clinical assessment. Participants from the FGD also gave feedback to improve understanding of the study information by providing details about the texture of the bronchoscope and disclosing the risks of the study. Feedback from the FGD was incorporated in the study information sheets by including visuals to improve understanding of the research.

Study recruitment was taking place at QECH. Health care workers at QECH were sensitized about the research project. I was however not able to attend the sensitization meetings with health care workers because I was in Chikwawa for data collection. The study team had a small office situated at the ward for TB patients. The office was being shared with another study team and there was limited space available. Research participants would often wait on the bench outside the office while waiting for their turn to meet the research staff. Since diagnosis of TB usually takes place in primary health facilities, the study team was having challenges to recruit research participants because there were few people presenting with TB to the hospital. This forced the PI to include other primary health facilities to meet the required sample size.

I had initially planned to spend one day per week at the office for the study team to observe interactions between health care workers and research participants. The research nurses however raised concerns in relation to my presence affecting confidentiality and other safety reasons. Since they were already having challenges in recruiting research participants, the research nurses offered to contact me when they identified new research participants so that I could meet them after their meeting. The challenge with this approach was that most of the research participants who were coming to the study office were already interested to participate in the research. As such, I did not meet individuals who had refused to participate in the research. While at the study office, I interacted with research participants and talked to them about the clinical trial as well as my ethnographic study. Since I could not conduct interviews at the hospital because it was challenging to safeguard participants confidentiality, I collected contact details for the research participants who were willing to be interviewed later.

Despite conducting the consultation FGD to improve informed consent processes, a majority of the research participants consented to participate in the research without full understanding of the research objectives. One of the participants understood bronchoscopy as a process that washes the lungs and claimed that the procedure made him feel better. This experience led me to reflect on the validity of informed consent processes and to explore issues of research benefits as defined by research participants versus researchers.

4.4.3 Unstructured and semi structured interviews

Unstructured interviews were used during participant observation to build rapport with informants and to broaden my understanding of several issues such as the social context, health research projects taking place in a village and more general issues. Through the unstructured interviews, I was able to identify informants to be included in semi structured interviews. Purposive sampling was used to select multiple players involved in research such

as: research participants, non-research participants, community leaders, research volunteers and study staff (See Table 4.2).

Semi Structured Interviews were used in order to have comparable data across different sources and case studies (Bernard, 1995). I also used SSI because they provide a flexible structure of open ended questions that allows the interviewer to pursue certain responses in more detail (Britten, 1995). A topic guide was developed to explore issues that I observed or heard during the ethnographic field work (See appendix 3). The topic guide covered issues of: experiences of research, understanding of health research, expectations from community engagement and reasons for accepting or refusing to participate in research. I pilot tested the topic guide with one informant in the urban case study and revised it accordingly to make sure that the questions were clear. Emerging themes from interviews with research participants and non-research participants were explored further in subsequent interviews with key informants such as community leaders and researchers to get their perspectives on certain themes. The topic guide was therefore revised to be relevant for each group to explore crosscutting as well as unique themes.

A total of 43 SSI were held with research participants, non-research participants, community leaders, health animators, CAG members and research staff from all the three case studies. I personally explained details of my study to the informants and invited them for SSI. Informants were asked to suggest a date, time and place for the interviews. Informed consent was obtained from informants prior to interviews to record the interviews using a digital recorder. Interviews were conducted in Chichewa and held in homes, community halls or classrooms as suggested by the informant. I facilitated all the interviews and used the topic guide very flexibly and iteratively by probing to get detailed responses as well as ensuring that the list of topics on the guide was covered. During interviews, I wrote down key phrases from the responses that needed to be explored further so that I did not interrupt the flow of

the conversation. At the end of the interview, I provided a reflective summary of the discussion and asked the informant to comment or ask questions. Informants were also asked If they could be contacted again to seek clarification on some issues. I wrote down a summary of the interviews to help me remember the discussion with informants and to explore the issues from other people's perspectives. In each case study, the decision to stop conducting further interviews was made when data saturation was reached, and new interviews did not yield new insights.

4.4.4 Focus Group Discussions

Focus Group Discussions were used to explore community experiences with health service providers, health interventions and engagement with researchers. I used FGD because they encouraged debate and discussions around key topics thereby allowing me to explore diverse perspectives and seek explanations for differing views (Smith P & Morrow R., 1996, Ritchie and Lewis, 2003).

Focus Group participants were purposively selected to include men and women who were either participating or not participating in the research. A total of 17 FGD were conducted with men and women in all the case studies. All the FGD were either held in classrooms or community halls. A topic guide was developed and used to facilitate the FGD covering issues of engagement with health services, engagement with researchers, community participation, perceived benefits and risks of research (See appendix 4).

I explained details of the study to all the focus group participants and consent was obtained from each participant prior to discussions. All the people who came to the venue for FGD consented to participate, there were however some people particularly men who did not attend. Each FGD had between 6 to 12 members and each participant was assigned a number. Numbers were used instead of names to track individual responses in the transcripts. I

facilitated all the FGD in the vernacular language. I started the discussions by asking participants to mention the organisations working in the community and the services offered to engage them to talk. Later on, participants were asked to mention any general concerns in the community, and these were written on a flip chart paper. Following this, a ranking exercise was undertaken to list the concerns in order of priority. This was followed by a discussion on the rationale for their ranking to understand where they situated health issues among their community concerns. The topic guide was used flexibly and iteratively to seek detailed responses on issues that emerged during the discussions as well as ensuring that all the topics were covered. At the end of the discussions, I presented a reflective summary of the discussions and participants were given an opportunity to ask questions or give comments.

One of the challenges experienced during the FGD was that some participants gave responses according to what was expected of them by researchers and not what they were doing in practice. Pressure to conform to socially acceptable viewpoints has also been acknowledged by others as one limitation of using FGD (Ritchie and Lewis, 2003). For instance, in one of the FGD, participants stated that all the people were using ITN and that they had no problems with them. I however observed and heard during the ethnographic field work that some people were using the ITN to cover bags of charcoal while others had received inadequate nets which meant that some family members were not using them. In such cases, I triangulated the findings by telling the participants my observations and asking them to explain why their responses were different from what was happening in practice. One of the explanations given was that they did not want to disclose such information for fear of negative implications. By triangulating data collection methods and sources, I was able to get multiple accounts on issues to get a holistic account of community engagement experiences.

The ethical dilemma however was to respect the views of the group that did not want me to disclose this information while other groups had already shared the information.

4.5 Data analysis

All the workshops, SSI and FGD were recorded using a digital recorder and transferred into a computer for back up. Each audio recording was assigned a unique code and transcribed in Chichewa by the researcher or experienced transcribers at MLW. All the transcripts and field notes were transferred into QSR Nvivo 10 and I organised the folders according to case study, location and data collection type. In addition, transcripts from SSI were assigned socio demographic characteristics of the informants such as age, education, location and gender. This was done to compare responses of informants with different levels of education and from different settings.

Data collection, coding and analysis were ongoing and iterative. Workshop proceedings were transcribed by the researcher while SSI and FGD were transcribed by experienced transcribers at MLW. I read first few transcripts from the workshops, SSIs, FGDs and field notes to develop codes emerging from the data. Later on, I developed a coding framework in QSR Nvivo 10 which I used to code all the transcripts as well as field notes (See Appendix 11). By coding the transcripts in Nvivo, I intended to review the data rigorously to identify commonalities and differences in response to particular issues. Coding also allows one to condense qualitative data into analysable units by creating categories from the data (Coffey and Atkinson, 1996).

During the coding process, I developed new nodes to take into consideration emerging issues from the data while other nodes were merged with similar nodes. I also developed annotations on some texts to note inconsistencies between what was reported and observed, contradictory responses among informants and other personal reflections in relation to the

literature. This process enabled me to explore some of the inconsistencies in the data during subsequent data collection and to pursue emerging issues in detail. Thus, emerging issues from the urban case study were included in the topic guide and further explored in subsequent data collection activities in other case studies. A similar process of data collection, coding and analysis was therefore followed in the rural case study and finally in the hospital case study. A total of 93 codes were developed deductively and inductively throughout the coding process.

Thematic analysis was used to analyse the findings by describing the results in relation to a particular theme, comparing responses among respondents within the same case study and across case studies (Bazeley, 2009). I also used interface analysis to understand social interactions among different stakeholders and how it affected community engagement processes. Interface analysis aims to understand interfaces at points where different actors intersect or in social interactions aimed to bridge and accommodate contesting stand points (Long, 1999). As already discussed in chapter two, community engagement ought to be more participatory, democratic or dialogic (Council for International Organisations of Medical Sciences., 2016, Bauer et al., 2007) rather than aim to increase scientific understanding. In these case studies, my interest was to understand how community engagement was used to bridge or accommodate contesting stand points of researchers and community.

I therefore read the coded data under each parent node and further grouped them into three main themes of social interactions, ethical issues and knowledge reproduction. This was done to sort the data and ensure that materials with similar content were located together (Ritchie and Lewis, 2003). Framework matrices were used to compare responses across cases to particular themes. To summarise the data, Nvivo models were used to show associations between themes in one case or between groups of cases. See Appendices 12-14 for examples

of a coded transcript, framework matrix and models that were used to synthesize the data into themes.

Following this, I started writing both descriptive and explanatory accounts of the data under each main theme. I started writing descriptive accounts of the data under social interactions, followed by ethical issues and knowledge re-production. Since there were so many linkages between the data, I had to reorganise the results under each main theme to ensure that they were presented systematically and to avoid repetitions. Two of my supervisors provided support during this analysis process by reviewing my initial drafts, challenging me to explore certain issues in detail and by pointing out repetitions in the results.

In order to develop explanatory accounts from the data, I re-read the transcripts and field notes to ensure that all the content has been considered and to understand what caused or influenced certain phenomena to occur. My explanatory accounts were therefore based on explicit reasons given by the participants themselves, implicit reasons inferred by putting together evidence, comparing my findings with other studies and relating the findings to my theoretical perspective on neo-colonialism. Since I used three different case studies, care was taken to ensure that I presented similarities and differences across the case studies and to offer explanations as to why community responses differed across the different settings. This process was however complex because I had to offer contradictory accounts to demonstrate how contextual issues affected community's response to community engagement, ethical issues and knowledge re-production in different settings. Verbatim quotes were used to support results.

4.6 Respondent validation

Respondent validation was done by discussing the main results with science communication staff, study teams, CAG members as well as study participants. According to Lewis and

Ritchie (2003), respondent validation involves presenting research findings to the research participants or groups with similar characteristics with an aim of confirming the interpretation of the findings.

I initially discussed preliminary results from the urban case study with the study team and they confirmed the results. Thereafter, I discussed the results to study teams from the rural and hospital based case studies, CAG members, staff at MLW, COM, and finally study participants. The discussions with different research stakeholder groups yielded insights on how to interpret the results and plan for community engagement more generally. For instance, some of the research staff indicated that it was challenging to incorporate community feedback because of potential risks to the quality of the research process, participating research communities and research participants. In addition, the research staff also pointed out some of the gaps in community engagement guidelines which I present in the results and discussion such as:

- Types of activities that should lead to genuine participatory processes in low literacy settings.
- Factors that should determine whether community engagement should teach communities or engage them in participatory processes.
- Whether it is ethical to plan sensitization or engagement meetings based on characteristics of target audience such as literacy.
- How to determine which feedback to incorporate or dismiss without frustrating communities and appearing to do cosmetic engagement.

Similarly, discussions of the results with CAG members and study participants yielded useful insights on how to interpret some of the results. I translated the Power point slides in Chichewa and discussed the results in three meetings that took place with CAG members and

study participants. Some of the issues these stakeholder groups stressed at the feedback session were that:

- Researchers must consult communities on research priorities.
- Researchers must inform the whole community about their planned activities.
- Researchers must understand the cultural differences and that they cannot engage in equitable discussions with communities.
- Research participants must receive a token of appreciation for participating in research.

Experiences from the respondent validation exercise challenged me to think of how dialogue between researchers and community should balance between incorporating local people's reality and promoting mutual benefits. Despite the success of this exercise to enhance data validity, there were several challenges and limitations which I will present in the following section.

4.7 Reflexivity

I am a woman who was born and trained in Malawi from primary school to university. I am therefore fluent in the vernacular language 'Chichewa' and familiar with most of the customs. After graduating from University of Malawi Chancellor College in 2005, I worked at an International Non-Governmental Organisation to coordinate programs aimed at supporting orphans and vulnerable children. Through this work experience and other short-term assignments with other organisations, I learnt to work with different community groups to implement projects.

In 2010, I moved to Blantyre and joined MLW as a social scientist. I later on pursued a Masters Degree in International Public Health at Liverpool School of Tropical Medicine in the UK for one year. Through the Masters Degree course, I was exposed to both quantitative

and qualitative research methods. At the time when I was starting my PhD, I had worked at MLW for three years in both qualitative and mixed methods research. My previous projects aimed to explore treatment seeking behaviour in response to acute bacterial meningitis (Desmond et al., 2013), the feasibility of introducing triage interventions in primary health facilities and a public engagement project using radio (Nyirenda et al., 2016). This PhD gave me the opportunity to learn and experience ethnographic research methods.

By conducting this research, my understanding of community engagement in health research was challenged. My understanding of community engagement was that it is a bottom up process where communities are involved throughout the research process. Through my involvement in the community engagement activities and consultation processes, I observed many complexities and dilemmas with community engagement processes. Firstly, community's views on research were sometimes in conflict with scientific or ethical procedures. Secondly, there were challenges to reach consensus during consultation processes. Thirdly, community's views constantly changed throughout the engagement process and were often shaped through social interactions with researchers as well as other community members and service providers. In addition, communities were diverse which presented challenges on who should speak on behalf of communities. These experiences led me to question the feasibility of engaging communities in participatory processes to design and implement research. These observations also challenged me to reflect on the aims of community engagement and raised several questions such as: how should dialogue be attained and sustained with communities? Who should be engaged in dialogue or asked for feedback on research? What makes them legitimate to provide feedback on behalf of other community members? How do we take into consideration diverse feedback? And how to ensure that community engagement benefits both researchers and community? With the

findings from this research, I expect to contribute to the current debates on legitimacy and relevance of the approaches used to engage communities in participatory processes.

Through my work experiences at MLW, I knew most of the research institutions in Blantyre, Science Communication staff and researchers. I had worked with Science Communication staff to evaluate their radio programme but I had not worked with people in all the case studies except for one field worker and one of the Principal Investigators. Since qualitative research is an interpretive research that requires interaction with participants for data, I was aware that my familiarity with the research institutions and some of the staff will influence my interpretation of findings as presented in section 4.7.2 under study limitations.

In order to overcome this challenge, I used reflexive triangulation to seek perspectives of other people on the same issues (Patton, 2002). I used various data collection approaches and involved different people to have multiple accounts and a holistic understanding of community engagement processes. By triangulating the data sources and data collection processes, I was hoping to enhance the validity of findings. Regular meetings were also held with my supervisors to discuss my interpretation of findings and they offered alternative ways to interpret the findings. Preliminary findings were discussed with researchers and participating research communities to get their feedback as presented in section 4.6.

4.7.1 Dilemmas of studying community engagement on other research projects

Conducting ethnography in other research projects presented a few challenges that could potentially jeopardise my relationships with research staff and communities. Firstly, some of the research staff appeared nervous that my research was going to uncover malpractices such that they would constantly ask for immediate feedback of my findings. On the other hand, some of the research staff perceived me as a community engagement expert and therefore expected advice on some issues. This presented a dilemma to respond to their needs to

maintain positive working relationships or risk getting contradictory and superficial results. Presenting preliminary feedback to the research teams or providing advice during data collection would have led to alterations in behaviour and contradictory results. As such, I discussed preliminary results with study teams after data collection.

The second challenge pertained to safeguarding informant's confidentiality when presenting preliminary results. For instance, I once attended a meeting where a research volunteer was teaching that every person is born with malaria and HIV. This led to a heated debate among the participants because some of the people wanted to find out why some people test HIV negative if people are born with HIV or Malaria. This experience presented an ethical dilemma to shift my role from an observer to a facilitator to correct the misconception. I however decided to inform the field workers to address it in subsequent meetings.

I was very conscious that presenting the example of the research volunteer who was relaying inaccurate information to researchers was going to affect my relationship with research volunteers and could potentially affect their roles in research. This presented another ethical dilemma to balance between minimising harm to the research volunteer and minimising harm to the community. By citing this example to the study team, it may have increased the risks to the research volunteer to be blamed for the misconceptions in the community, whereas failure to address these challenges could lead to more harm in the community. I therefore resorted to address this issue while in the field and brought these issues to the attention of study teams without disclosing details of the research volunteer to safeguard their confidentiality.

Thirdly, presenting preliminary results to the study teams and science communication staff yielded additional insights as well as resistance and anxiety. By conducting ethnography, I made friends with research staff and science communication staff that either presented challenges or facilitated presentation of results. For example, I was nervous to present

findings from the workshop with CAG members that workshop participants had limited understanding of their roles and that they did not effectively represent community's concerns of ethical relevance. After Science Communication staff had kindly helped to organise the workshops and the CAG members had shared their roles and challenges, I felt uncomfortable to provide feedback on their inefficiencies to represent community's concerns. On the other hand, these results made some of the Science Communication staff to think that they were going to be perceived as ineffective in their job to engage with CAG members. Through discussions and negotiations, we came to an agreement to collectively use these unexpected results to improve practice. Science communication staff eventually used the results to set up a new CAG in Blantyre and Chikwawa. My regular engagement with the staff helped to build rapport and not to be seen as a critic of their work.

Fourthly, another challenge arose when sharing the results with the wider audience through publications because I was aware that the Science communication team may feel uncomfortable to disseminate the results to the public. I therefore resorted to having discussions of my presentations and publications with the team before sharing with the wider audience to enhance transparency. Initially, we agreed to make the research institution where the research was being conducted anonymous. Our affiliations to MLW however could lead people to figure out that the study was conducted at MLW. We eventually agreed to indicate that the research was conducted at MLW and use this as an example of using research to improve community engagement practice. This process of engaging them in the analysis and presentation of results proved useful because it offered additional insights that enriched the data.

Fifthly, the study results presented practical questions around engaging communities in health research. While community engagement in health research is promoted as a means of increasing informed participation, there were a few challenges. For instance, in the urban

case study researchers responded to feedback from communities to inform parents about the study. The assumption held by these communities was that knowledge of research objectives increased participation. This assumption was however challenged when researchers experienced challenges to recruit research participants from school communities that informed parents. Related to this, I also observed that most of the people who participated in research had low literacy levels while people with higher literacy refused to participate in research. These results could imply that, a lack of understanding of research objectives facilitated participation in research which raises concerns about the validity of using community engagement to improve informed consent in settings with low literacy.

Finally, as a Malawian researcher, some community members saw me as a point of contact to express their concerns to researchers. The nature of research however requires adequate time for data collection and analysis. Translation of results into practice also requires adequate time, availability of resources and willingness of funders to incorporate community needs in the research or development agenda. As such, I was not able to address some of their concerns raised in this study.

4.7.2 Study limitations

The main limitation of this study was that data collection, coding and analysis were mostly done by me. As such, my identity as a female Malawian researcher may have shaped how I accessed the informants, how they responded to my questions and how I interpreted the results. Even though I am a Malawian who is fluent in the vernacular language and some of the cultural norms, I got a sense that communities either perceived me as an insider, outsider or something in between. All these perceptions affected or facilitated my interactions with them and the data that I collected as it will be explained in subsequent paragraphs.

As a Malawian, informants sometimes assumed that I was already aware of certain issues and therefore did not expect me to seek more details. For instance, some people believed that *'sleeping under the mosquito net affected them in the bedroom.'* As a researcher, I needed to understand whether it affects their sex drive or ability to reproduce. These discussions however made some people uncomfortable because they assumed that I knew the meaning of *'being affected in the bedroom.'* On the other hand, my local knowledge of other issues may also have led me to have assumptions of their meanings of phrases without seeking for more elaborate responses.

As a researcher who was interacting with multiple stakeholders such as researchers, frontline workers, community members and research participants, I was often confronted with diverse views of these stakeholders on issues. Such experiences presented challenges on how to balance these conflicting views and whose views to be considered as valid. One of the most notable issues was that community members 'knowledge' were often based on previous experiences with research, advice from friends and their interpretations of research practices alongside their local knowledge. Whereas, researchers' 'knowledge' was based on empirical information or text book information. For instance, some community members believed that participation in research led to death because they drew so much blood, while researchers dismissed such beliefs as rumours. I have therefore attempted to unpack these conflicting views of communities and researchers in this thesis without being biased towards the views of a particular group.

4.8 Ethical considerations

This study was approved by University of Malawi, College of Medicine Research Ethics Committee and Liverpool School of Tropical Medicine Research Ethics Committee in UK. Consent to conduct the study was sought from the directors of research institutions, study coordinators and village heads prior to data collection. This was in accordance to Ethical

Guidelines of the Association of Social Anthropologists of the UK and the Commonwealth which state that "*in some cases, consent will initially need to be sought from individual gatekeepers such as community leaders and officials: chiefs, local councillors, headmen, hospital consultants, trade union leaders..."* (Association of Social Anthropologists of the UK and the Commonwealth., 2011).

After identifying the case studies, I arranged a meeting with the study coordinator for the urban case study to discuss my research proposal and seek consent to use their research project as a case study. The study coordinator consulted the principal investigators and they consented to allow me to study community engagement in their research project. I also explained details of my study to the study team so that they were all aware of my study objectives. A similar process was followed for the rural and hospital based case studies and the Principal investigators consented to use their research projects as case studies.

Thereafter, consent was again sought from local leaders to conduct an ethnographic study in their villages. I explained details of the study to the village heads, presented relevant documentation about the project and they gave verbal consent to conduct the study in their villages. This was done to ensure that the research was conducted in ways that recognise existing social structures. There were however two village heads from the community based case studies that consented to have the ethnography study in their villages but refused to be interviewed as key informants. One of the reasons given by the village head in the urban case study was that he had not been involved in the research project. The other village head in the rural case study indicated that I should interview his wife because she was aware of most of the issues compared to him.

Informed consent was sought on an individual basis from all the participants. Information about the study was presented to individuals and they were given an opportunity ask

questions, consult other people and provide a signature or a thumbprint to consent for the study. Individuals who declined to participate in focus groups or interviews were not included in the study. During community engagement meetings, verbal consent was sought to take photographs because standard procedures for obtaining written consent were problematic. I have attached study information sheets and consent forms used for FGD and SSI in appendices seven to ten.

All study participants were ensured anonymity and confidentiality of personal information during the consenting process. In order to ensure confidentiality of all study participants, I used unique codes to label audio recordings and transcripts. Audio recordings and transcripts were also saved in password protected computers accessed by me and transcribers at MLW only. I also used codes instead of names to ensure privacy and anonymity when presenting study findings.

4.9 Conclusion

In this chapter, I presented the aims of the study, study design, data collection, analysis processes and study limitations.

A qualitative study design was employed to understand the purpose, relevance and benefits of community engagement in three ethnographic case studies. Multiple data collection techniques such as participatory workshops, participant observation, interviews and FGD with multiple research stakeholders were used to triangulate findings.

Thematic analysis was used to present the findings under three main themes of social interactions among research stakeholders, ethical issues arising from community engagement and finally, knowledge re-production and study acceptability in the context of community engagement. Preliminary results were discussed with different stakeholder groups and

feedback was incorporated in the final results. In chapter five, I will describe the results under the theme of factors shaping community engagement in health research.

Chapter 5: Factors shaping community engagement in health research

5.1 Introduction

During my field work in Chikwawa and Blantyre, I often observed that when research staff or outsiders went to villages to hold meetings, community members reserved chairs or mats for research staff next to the community leaders, teachers and other respected people. A majority of women, youths and children sat on the ground if there were inadequate chairs and mats as shown in figure 5.1. This made me realise that villagers respected the research staff. I therefore wondered how social norms and local power structures influenced community engagement and conduct of health research.

A common saying in the villages was that *'a visitor comes with a sharp knife'* which ironically meant that visitors came with new knowledge to make positive contribution. I however felt that this local saying could also have double meanings and imply that communities viewed visitors with distrust that they could potentially harm them with the *'sharp knife'*. Certainly, a number of service providers offered top-down services directed towards educating the communities or addressing community needs. Despite this, most of the participating research communities were still burdened with poverty and lacked essential services such as health facilities, schools and roads. It became clear to me that community members expected to acquire knowledge and other forms of assistance from health researchers too. This led me to think that communities had a more instrumental role on how to engage with research staff even though the guidelines on community engagement promoted participatory community engagement processes.

This chapter aims to discuss how social norms and power differences between research stakeholders shape community engagement practices and in turn influence community members to maximize research participation to address their needs. In addition, I will also

show how powerful outsiders such as research institutions and research staff drive the research agenda and determine the terms of engagement with communities.

While a number of publications have focused on social interactions among research stakeholders, these have largely focused on challenges of health care workers and other frontline workers to balance their professional roles, research roles as well as fulfill their kinship roles (Angwenyi et al., 2013, Chantler et al., 2013, Okello et al., 2013, Molyneux and Geissler, 2008, Geissler et al., 2008). Collectively, these studies have shown that social relations between frontline workers and communities influence community members decisions to consent or refuse to participate in research and thereby compromise ethical research practice. Few studies have however explored how local histories and structural inequalities shape social relations between multiple research stakeholders to perpetuate deficit models of engagement and this study seeks to address this knowledge gap. I will therefore start by providing a description of the engagement processes across the three case studies (5.2) and explore factors that shape community engagement processes (5.3). These include: contradictory expectations of research staff and community members from engagement (5.3.1); historical engagement with other service providers (5.3.4); pre-existing power relations among research stakeholders (5.3.5); effects of research practices on social relations and community engagement (5.3.6) and finally, conflicting interests of researchers and research volunteers (5.3.7).

Figure 5.1: Community engagement activities in Chikwawa and Blantyre

2

5.2 An overview of community engagement activities and stakeholders involved in research

The underlying aims of community engagement activities employed in the two community based research projects (the urban and rural based case studies) were to engage communities in two-way dialogue and to enhance community participation. In practice however, community engagement activities reflected deficit models of engagement because the main aim of engagement was to inform communities about the studies in order to increase participation. These deficit models of increasing scientific literacy have however been criticised in favour of collaborative partnerships when designing research projects (Bauer et al., 2007, Davies, 2011, Council for International Organisations of Medical Sciences., 2016). On the other hand, the hospital based study used consultation FGDs to seek feedback on study information sheets and improve informed participation in the research. Thus, the researchers did not intend to engage in collaborative partnerships with the target community.

The two community based research projects described their communities as the geographical location where research participants resided. Whereas the hospital based study defined their community as people with a certain disease condition and their carers. Even though the two

*The man sitting on the mat was the facilitator who sat down in order to be included in the picture

community research projects were targeting geographical locations as their communities, the urban case study was targeting children attending selected schools whereas the rural case study was targeting all households in the intervention villages. In the urban and rural case studies, researchers engaged with a mix of potential research participants, current research participants and non-research participants whereas the hospital case study involved consultations with a community of people with TB and their carers who were not participants in the bronchoscopy research.

The hospital based study did not have study specific community engagement activities. One of the reasons why they did not have study specific community engagement activities was because they were not targeting research participants from a specific geographical location but rather a community of people with TB who did not necessarily reside in the same geographical location. The assumption held by the research staff was that a community is a group of people residing in a specific geographic location. As such, community engagement activities were normally planned for community based studies compared to hospital based studies unless the hospital based study was targeting a specific geographic location.

The study design and targeted population was seen to determine which stakeholders to engage with. Since the urban based case study involved school children, activities were planned to engage with relevant stakeholders such as Primary Education Advisors (PEAs), Parents Teacher Association committees (PTAs), parents and students. On the other hand, the rural case study involved all households in a village and therefore targeted village heads, health animators, committees and all the residents in a village. While community engagement activities in the urban and hospital based case studies were one off events prior to study implementation, community participation throughout study implementation was required in the rural case study. I have categorised the stakeholders involved in research into five groups

of: government and other service providers, frontline workers/research staff, research volunteers, community and research participants as illustrated in figure 5.2.

In all the case studies, a team of principal investigators comprised of both Malawians and non-Malawians were involved in the development of the study protocols. The principal investigators were highly trained medical professionals with PhDs or Masters Degrees. These principal investigators were therefore highly regarded by the communities and research staff because of their education. The principal investigators hired and trained research staff on the study protocols. In all the three case studies, the research staff included research nurses and other staff who did not have medical training. Most of the research staff already had prior experiences of working in a research project. These research staff were mostly Malawians but did not necessarily reside in the communities where research was taking place. In the urban case study, some of the research staff were residents in the geographical location where research was taking place while the rural case study had a mix of both residents and other staff who had relocated to Chikwawa because of employment. These research staff were accountable to researchers and mostly involved in the translation of the study protocol into practice by communicating the research projects, recruiting study participants and responding to community concerns. Most of the negotiations between researchers and community were therefore handled by these people and their understanding of community engagement influenced practice. In the section that follows, I will discuss expectations of research staff and community members from community engagement.

Figure 5.2: A summary of the main stakeholders involved in the case studies

1. **Research participants:** includes children and adults who consented to take part in the main research projects or interventions.
2. **Community**: refers to residents in the geographical location where the study took place or a group of people affected by the same disease.
3. **Research volunteers**: refers to members of the community who were selected by fellow community members or village leaders to assist with specific roles defined by researchers. This includes health animators, CAG members and committee members for LSM, HI and other interventions in the community.
4. **Front line workers/research staff:** refers to research staff who are employed by research institutions to recruit study participants or to assist with communication.
5. **Government officials, NGO staff and other decision makers:** includes people who may not be part of the community or the research team but they have a stake in the research. This includes NGO staff, government officials and members of ethical review boards.

5.3 Factors shaping community engagement practices

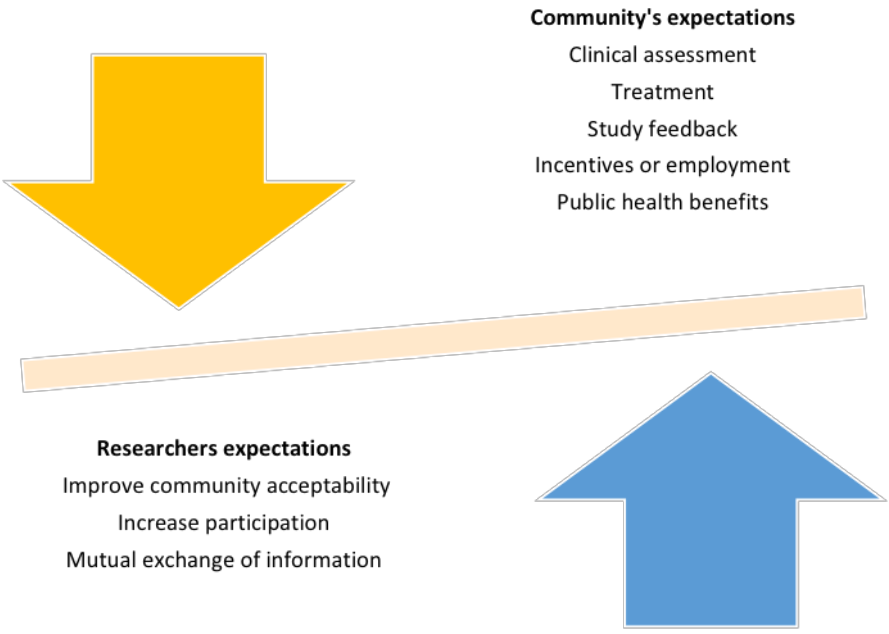
5.3.1 Disconnect between research staff and community members expectations

Since ethical guidelines on community engagement stressed that communities should determine for themselves research projects that are responsive to community needs (Emanuel et al., 2004, Council for International Organisations of Medical Sciences., 2016), I wondered who defines community needs and if the community engagement approaches were responsive to community needs. Through FGDs and interviews with research staff, community members and research participants, I therefore explored expectations of these stakeholder groups from community engagement.

I noted that responses from these stakeholder groups on expectations from engagement reflected unequal power relations, where ideas of research staff to increase scientific understanding and study participation through community engagement were more privileged and effected in practice. On the other hand, community's views or needs for engagement were not always effected and reflected a perception that they considered themselves as inferior and dependent on researchers to address their needs. According to Bermúdez (2016), research practices demonstrate neo-colonial effects when the ideas of powerful groups are privileged while the less powerful groups believe that the ideas of the most powerful groups are more legitimate, and they internalise this inferiority. While researchers used community engagement to increase understanding of research with an aim of improving participation, responses from community members indicated that they expected researchers to alleviate their problems rather than work with them as collaborators (See figure 5.3). This shows that despite the increasing emphasis on active engagement of communities in designing a study (Holzer et al., 2015, Minkler, 2005), participating research communities did not expect to be actively engaged in designing or implementing the studies but they expected to benefit from research.

Upon investigating the main reasons for engaging communities, responses from the research staff indicated three cross-cutting themes: improving community acceptability, participation and mutual learning. Other less occurring ideas were that community engagement improved joint decision making, community ownership and sustainability of interventions. While some of the community members agreed that having information about a study improved acceptability and participation, a majority of community members indicated that they expected to benefit from clinical assessment, treatment, feedback on study results and to access incentives (See figure 5.3 below). This shows that community members expectations from engaging with researchers were driven by their individual needs for health services and other essential services.

Figure 5.3: Researchers versus community expectations



5.3.2 Researchers expectations from engagement processes

Engaging to improve community acceptability of research

A variety of perspectives that reflected neo-colonial patterns of determining the terms of engagement were expressed by research staff. Given the ethical requirements in health research, most of the research staff felt that informing communities about research improved community acceptability and informed consent. Since the urban case study involved school going children, informants explained that it was necessary to recognise existing social structures by informing PEAs and PTAs in order to seek their approval to conduct the study in schools. Similarly, in the rural case study most of the informants stated that it was necessary to respect existing social structures and seek approval from village heads. According to the field workers, they believed that community leaders who have been informed about a study were more supportive to field workers by offering advice relevant to a specific context. Such community leaders were also able to clear misconceptions and address community concerns by sharing their knowledge of the study objectives. Since community leaders were powerful, their understanding and support for the study was seen as key to advance positive perceptions of the study in the whole community as well as participation.

Providing information about a study was also seen by the research staff as essential to improve acceptability of a study by 'dispelling misconceptions and fears' with research. In both settings, there were beliefs that health interventions or research procedures were satanic (associated with devil worshiping) or that they led to infertility. The research staff assumed that these rumours were due to illiteracy or lack of knowledge about the research objectives. Since information in the communities was normally shared using oral communication, the research staff stated that informing communities about research helped to promote positive discussions in favour of the study which in turn prevented negative rumours from arising. The assumptions held by the research staff were that community members who were aware

of the research objectives were able to share accurate information about a study and these minimized bad rumours in the community.

In addition, frontline workers stated that they felt welcome and safe to work with communities that were informed about the research. In the urban case study, some of the front-line workers and village heads reported that some research staff had been beaten by community members because they were being suspected of satanism. The informants felt that communities were hostile to strangers including researchers if they were not properly informed of their intentions in the villages. Informing communities about research was therefore seen as a means of dispelling community's misconceptions and fears with research. Research staff therefore informed communities about research in order to minimise risks of being attacked by community members.

Engaging to ensure participation in research

A common view among research staff, research volunteers and community members in the urban and rural case studies was that communities needed to be informed about a study to improve participation in research. Research staff from the urban case study stated that their community engagement strategy was designed to ensure that communities understand the study objectives and benefits. They thought that having an understanding of study objectives and benefits empowered people to make informed decisions. Since some community members preferred not to participate in research due to their interpretation of study objectives, informing communities about a study was seen as a way of respecting the community's right to information and improving informed consent. A field worker and a research staff in the following quotes provide typical responses of why researchers used community engagement to inform communities about research.

'The reason why we developed the community engagement strategy was to ensure that the community understand the intentions of the study, its objectives, and its benefits to the community so that they agree to participate'

Male frontline worker, Urban setting-GI 007

'As a parent or as a community member, if I observe that some people are walking around with clipboards and black bags, I would want to know who they are. If they were people in the schools of my children and if children are being swabbed, I would want to know what is going on and why is this happening. So, I think that's why it is important to inform all the parents, to be transparent and for them to understand what's going on and also to try to avoid animosity from parents'

Male senior research staff, urban setting-SSI 009

These quotes provide a good illustration that community engagement was used to inform communities about research to improve informed participation, community awareness of the research project, recruitment of study participants and to minimize community resistance to research activities. In the first quote, the front-line worker states that they used community engagement to raise awareness of the research objectives and to increase research participation. In the second quote, the researcher also supports the idea of informing communities about research from multiple perspectives as a father, community member as well as a researcher.

The rural case study involved collective participation of community members to implement interventions aimed to prevent malaria. To achieve this, research staff educated communities

about malaria with an aim of improving participation and adoption of malaria control interventions as indicated in the training manual for health animators.

> *'The ultimate goal of the malaria educational activities is to increase participation and adoption of malaria prevention and control interventions by household members of targeted communities thereby facilitating collective action against malaria at village level'*
>
> Training manual for HA on malaria prevention and control

Similar to the urban case study, this shows that community engagement was also used in the rural case study to ensure study participation and community adoption of malaria control interventions.

Engaging to improve accuracy and quality of data

Another rationale for informing communities about research was that it improved quality and accuracy of data. There was a concern that lack of information about study objectives may present risks of over reporting or under reporting certain information with expectations of receiving more handouts. For instance, some research participants may not provide adequate information if they thought that they will not get any assistance if they provide accurate information. Informing communities about research was therefore seen as a means of improving transparency by ensuring that communities understood research procedures and what they were expected to do. This was seen to prevent confusion and frustrations from communities and ultimately improve the quality of research. The research staff stated that people who understood the rationale for the study were likely to give accurate information as explained below by a female research staff.

'If we just take it that we are researchers and we shouldn't inform communities about our work, we may compromise the quality of our results. You may find that people are hesitant to give information, or they may hide information that they could have given you...instead of just saying I have five children they may say I have eight children because they may think ii! Maybe they will give out food. This may affect our data'

Female research staff, urban setting-Group Interview 007

Informing communities about research objectives was therefore seen to minimize misrepresentation of information. Research participants were likely to give accurate information if they knew that the information that they provided would not affect the amount of assistance that they would receive from service providers.

Engaging to improve mutual exchange of information

Research staff from the urban and rural case studies reported that community engagement helped to improve mutual exchange of information between researchers and communities. Through interaction with communities, research staff claimed that they benefited from learning about community perspectives on particular issues as well as misconceptions prevailing in the community. For instance, in the urban case study, research staff stated that some community members were spreading rumours that the study team had gone to inject children with germs. Knowledge of such negative rumours helped the study team to clarify the study aims to community members. Similarly, in the rural case study, most people used to keep their water in clay pots and believed that the mosquito larvae *(nkaning'wining'wi)* cooled the water. Knowledge of such issues helped the research staff to raise awareness of

the link between mosquito larvae and malaria and to discourage this practice by draining the water.

Apart from the examples given above, there was little evidence to suggest that community engagement improved mutual learning. For instance, some participants raised concerns with some aspects of the interventions such as bed nets, house improvement and randomisation of research participants for malaria screening. The researchers distributed bed nets to households to prevent mosquito bites. Most of the research participants however indicated that the bed nets were irritating their skin. Similarly, some participants also raised concerns that closing the eaves or covering the windows with iron mesh was making their houses hot since the climate was already hot in Chikwawa. In addition, random selection of participants for malaria tests in the villages created demand in the communities for malaria tests. Community members however expressed concerns that the researchers did not consider conducting malaria tests particularly among people who were not randomly selected to participate in the research. In the quote below, a research volunteer in the rural setting articulates why some community members felt this way.

> *'According to their research, they may select three people to test and if they find them [with malaria] they give them medication. And yet people who go to health facility for malaria test may be 10 to 11 per day, so they come and select two people because they are conducting a research. This is where I feel things are not right, it is better to test the 10 people who have gone to the health facility and assist them with medication even from the villages. Instead of just picking two and saying the rest should come to the health facility'*
>
> Research volunteers, rural setting-SSI 005

Even though the research staff indicated that they engaged communities to improve mutual exchange of information, this quote shows that community views in relation to malaria tests were not taken into consideration by the researchers. In this case, community members felt that malaria tests should be done among ill people in the villages to ease them from walking long distances to health facilities rather than in randomly selected people who were not sick. This highlights challenges with community engagement to respond to community views that were in conflict with the study design.

Engaging to improve joint decision making, ownership and sustainability

Other less popular themes in support of community engagement in the rural case study were that it improved joint decision making between researchers and community, ownership and sustainability of the interventions. These views were probably drawn from the literature by the research staff because informants were unable to provide examples of how their community engagement led to ownership and sustainability of interventions since the study was ongoing. Even though the interventions were 'community led' by research volunteers, some community members were not willing to participate in the interventions across the different contexts. In addition, some people were requesting for items like nails to fix their iron mesh or gum boots when draining breeding sites for mosquitoes as this woman from a rural setting noted.

> *'The problem was that, some people were giving problems to put the iron mesh, they were saying that they do not have money to buy nails. It would have been better if the researchers were also giving us some nails'*
>
> Female participant, rural setting-FGD015

Community requests for items such as nails therefore raise questions on community ownership of the project and sustainability of interventions beyond the project's life span.

Overall, community engagement was used in these case studies to improve study acceptability and participation rather than engage communities as collaborators. This shows that the researchers aim of engagement fell short from the ideals of community engagement. While the researchers engaged with communities to facilitate study implementation, community members had contradictory expectations from engagement as shown in section 5.3.3.

5.3.3 Community members contradictory expectations from engagement

Research participants and other community members were asked to express their views on how they wish to be engaged and why they engaged in research. A variety of perspectives were expressed particularly in the urban settings due to broader social relations with service providers. Some community members expected to be engaged as volunteers or employed staff while others expected clinical assessment, treatment and study feedback. Thus, historical experiences of being recipients of information or services from outsiders potentially led community members to expect researchers to address their health problems and financial needs rather than work with them.

Conflicting views on community members involvement as research volunteers

One of the common themes that emerged from the urban and rural case studies was that community members should be engaged as volunteers and assist to implement the research. One of the participants from a rural case study commented *'aah!! I would love to help people in this research and encourage them to participate so that this research must not slow down...'* (Female research participant, rural setting SSI 002). Another research participant from an urban case study stated: *'As for me, I would love to encourage people in the village to participate in research because some people refuse to participate [laughs]'* (Female research participant, urban setting- SSI 009). Informants may have expressed these views because they

live in settings with high levels of unemployment and poverty. Getting employment or working as volunteers was probably seen as more attractive and beneficial than participating in the research because of the financial gains and incentives.

Conflicting discourses were however observed in relation to engaging community members as volunteers particularly among non-participating community members in the urban setting. Concerns were raised by some of the non-participating community members including village leaders that researchers only engaged health care workers as paid employees while community members were asked to volunteer without any wage. Even though some research participants indicated that they wished to be engaged as research volunteers, other community members felt that engaging community members to serve researchers interests without any wage was exploitative. Differing views of researchers and community members on study benefits and exploitation will be explored in chapter six.

Access to clinical care, treatment and other incentives

A majority of research participants from the urban and hospital based case studies also indicated that they participated in research in order to benefit from clinical assessment, treatment, test results, financial or material incentives. While in the rural case study, a recurrent theme in the interviews was a sense amongst research participants that they participated in research to eradicate malaria. Responses to this differed across informants probably due to the differences in study design, historical experiences and social relations with service providers described in section 5.3.4 and 5.3.6. Since the urban and hospital based case studies involved invasive medical procedures and were conducted in urban settings where there had been many research projects, a majority of research subjects participated in research to know their test result, access treatment as well as incentives. In the following quote, a father to a research participant provides a typical expression of why some

parents consented to have their children participate in research: *'we thought it was good that one of our children was selected [to participate in the research], because our family shall know whether we have this disease through this child',* (Male research participant, urban-SSI 013). Only few research participants in this case study participated in research to support attainment of study objectives as defined by researchers. In contrast, a majority of research subjects in the rural case study demonstrated that their intentions to participate in research were in line with study objectives to eradicate malaria. Factors that contributed to variations in terms of understanding of the research objectives have been presented in chapter seven.

In summary, I have shown that both researchers and community members did not seek collaborative partnerships. While the researchers used community engagement to improve study acceptability and participation, community members expected clinical assessment, treatment, incentives and employment from community engagement. Previous challenges to recruit study participants as well as scientific requirements to attain an optimum sample size may have potentially led researchers to use community engagement as a means of improving study acceptability and participation. Similarly, the absence or poor quality of health services may have led community members to expect researchers to provide quality health services. One of the issues that emerges from these findings is that, even though ethical guidelines promoted collaborative partnerships, none of the stakeholder groups expected collaborative partnerships. Community engagement processes were therefore shaped by historical experiences of engagement as well as power differences among research stakeholders as discussed in subsequent sections.

5.3.4 "*That experience is still stuck in people's minds*" Historical engagement with other service providers

Historical experiences with service providers, pre-existing social norms of engaging with outsiders, as well as the political and socio-economic context was seen to shape these

differing expectations from community engagement activities or research (See figure 5.3). When community members were asked to state how they wished to be engaged, none of the community members expected collaborative partnerships with researchers probably because they were never exposed to equitable collaborative partnerships. Community members were exposed to top-down processes of service delivery and hence uninformed that their views could influence research practice. Thus, historical experiences of being the recipients of information or services from outsiders potentially led community members to depend on researchers to address their health problems rather than work with them. In addition, power inequalities between community leaders, community members and outsiders also influenced community engagement practices. Detailed examples of how community engagement was shaped by historical experiences with other service providers and power inequalities among research stakeholders will be discussed in this section.

Experiences from the rural case study

Previous experiences with service providers, research collaborators and other research projects were seen to facilitate community's expectations of being engaged as recipients of assistance from outsiders rather than collaborators. The rural based case study was implemented in settings that surrounded Majete Game Reserve where the Hunger Project and African Parks were also working. In focal area X, an epicentre constructed by communities with financial support from the Hunger Project was established to support the villages with various programs on food security, micro finance, health and others. Since Hunger Project was the first NGO to mobilise communities to participate in the construction of the epicentre, pre-existing community mobilisation strategies facilitated collective participation in the malaria control interventions in focal area X compared to villages in focal area Y. Most of the community members responded favourably to the malaria control interventions probably because they were exposed to collective participation in community development projects led

by outsiders. The community members also viewed the projects by Hunger project as beneficial because they addressed their immediate needs such as food security, access to health care and microcredit. Previous experiences of being engaged as recipients of assistance therefore facilitated community's response to the study as project beneficiaries rather than collaborators.

In contrast, mistrust between community members and research collaborators affected community response in focal area Y because of their previous negative experiences with African Parks. Before the creation of Majete game reserve, informants from selected villages in focal areas Y indicated that African Parks evacuated people from their original homes in order to create the game reserve. A majority of community members in focal area Y felt betrayed by African Parks for taking their best arable land and enclosing it in an electric fence for the benefit of wild animals and tourists. They claimed that enclosing the game reserve in a fence denied them access to fertile lands, fish, animals and drinking water for their livestock. In addition, FGD participants stated that they were engaged as volunteers to construct the camp site for tourists, but they claimed that they did not see the direct benefit of having the game reserve close by. Despite the attempts by African Parks to establish CBOs to address community needs such as education, food security and economic empowerment, some community members were still resentful towards African Parks for being unable to fulfil their promises. The community members were resentful partly because an alternative source of income was to cut down trees and engage in charcoal making business but African Parks was preventing deforestation and they were confiscating the charcoal. These issues therefore led to mistrust between community leaders, community members as well as African Parks because community members thought that the village leaders signed up to this arrangement which they viewed as exploitative. These experiences also led to suspicions and mistrust with other service providers because they feared that they would be exploited again.

For instance, when research staff were enumerating households for research purposes, this aroused fear in some participants that they were numbering houses in order to relocate them to a hilly place. In such cases where there was pre-existing mistrust between villagers and community leaders, information alone did not result in community acceptability of an intervention. Rather, previous exposure to inequitable partnerships with service providers strengthened community's views of social relations between local elites and local communities as exploitative. In the following quote, a woman from one of the villages in the rural case study explains how community participation was affected by previous disappointments with one of the research collaborators:

> *We have now realised that it [African Parks] is now like a company where they generate income because when we pass by there, we see cars going and coming back we see all that. There are people who work there and receive money...but they have not fulfilled the promises made to us that we will do so, so and so...all that didn't happen and that is why there is enmity because these people come to entice us when they want things from us...that is why people are refusing to take part...it's because people still have this picture that these people just want to exploit us. And that image [history] is still stuck in people's minds*
>
> Female FGD participant, rural setting-FGD014

The community members felt betrayed with African Parks because they took away their best arable land, denied local communities sources of their livelihoods and in turn used the land for the benefit of tourists and African parks. Past disappointments with service providers therefore led some community members to fear that the researchers could cause more harm.

Experiences from the urban case study

Similarly, previous experience with research and other service providers was also seen to shape community's expectations and response to the community engagement activities in the urban case study. In this case study, there had been a number of research projects and NGOs both at health facility and community level who offered treatment to study participants and other incentives. For instance, FGD participants mentioned that research institutions such as Johns Hopkins and Blantyre Malaria project offered clinical assessment and treatment to research participants at the facility. Several other NGOs such as SOS, Dream, DAPP and Word Alive also supported people living with HIV/AIDS and orphans with home based care, housing, school fees and school uniforms. Community's expectations from engaging with researchers were therefore shaped by their previous exposure to benefits offered by researchers. Historical experiences with other service providers as recipients of aid rather than collaborators therefore shaped their expectations from engagement.

In summary, given the historical background in each context, community members did not expect collaborative partnerships with researchers. Community members expectations and response to the community engagement activities were shaped by broader social relations with service providers. Thus, colonial discourses of local communities as 'impoverished or disease burdened' may have important implications on how communities engage with researchers as 'helpers' rather than collaborators. Taken together, these results raise questions on how community engagement can effectively promote equitable collaborative partnerships in neo-colonial settings where communities are not exposed to these collaborative ideals. In the following section, I will discuss how power inequalities among stakeholder groups shaped community engagement practice.

5.3.5 Pre-existing power relations among stakeholder groups

While variations among research staff's aims of community engagement influenced the community engagement processes, pre-existing power imbalances between or within stakeholder groups also played an instrumental role on engagement processes. According to ethical guidelines on health research, community engagement should aim to promote meaningful participatory processes that involve communities in the design and implementation of research (Council for International Organisations of Medical Sciences., 2016). This implies that dialogue in public/community engagement activities must strive towards equitable interactions among research stakeholders with diverse views (Davies, 2011). On the other hand, scientific rules sustain power inequalities by presenting scientific information as 'expert knowledge' while discrediting other types of knowledge as 'lay knowledge' (Gaventa, 2001). Thus, both visible and invisible forms of power due to organizational hierarchy and scientific knowledge were seen to constrain less powerful individuals to speak their views concerning research. In addition, differences between researchers and community members on power and scientific expertise were also seen to determine which views to dismiss or incorporate in the research. As such, the ideals around democratic or equal participation were difficult to attain and engagement processes reflected deficit models of informing communities about research. This theme was evident particularly in the urban case study where meetings were held with various stakeholder groups to consult or inform them about the research.

Experiences from the urban case study

Power differentials between research staff and other stakeholder groups due to research literacy potentially constrained some stakeholders to express their views concerning the research design. In this setting, most people were socialised to respect or be submissive to people considered as senior in terms of age, gender, education or social position. For

instance, young women were socialised to be submissive and respectful to senior people by kneeling down when greeting or talking to them while young boys were expected to bend or bow. Similarly, most people were socialised to give similar respect to visitors (outsiders) by kneeling down when greeting them, offering them the best seat, meals and other privileges. These social norms were deep rooted and consequently reinforced invisible power relations between research staff, community leaders, research volunteers and community members.

Even though the aims of engaging various stakeholder groups were meant to engage communities in two-way dialogue, a majority of the research stakeholders contributed towards the community engagement plans rather than the scientific design of the study. A number of reasons could possibly explain this. Firstly, lack of scientific expertise by most of the community members probably constrained individuals to express their views on the research design. Secondly, social norms of respecting outsiders as having the relevant expertise to address community problems may also have led the stakeholders not to express their views concerning the research. Thirdly, the political context and historical experiences of being engaged as recipients of projects rather than collaborators may have shaped the stakeholders' response to the discussions. Given that there are generally challenges to achieve democratic participation in Malawi (Magolowondo, 2007, Chiweza, 2007, Mwalubunju, 2007), one may argue that the political context may not support democratic participation in international research as intended in international guidelines.

Both visible and invisible forms of power across the research stakeholders' groups were seen to determine which feedback to incorporate or dismiss in the research. All the meetings had a similar format where the research was presented to participants followed by a discussion. The initial meeting was held with PEAs and other officials from the District Education Office who were entrusted with the responsibilities of supervising clusters of primary schools. Even though this stakeholder group was highly educated compared to other community stakeholder

groups, they did not give any advice on the research design. This could be because the PEAs considered the researchers as having the relevant expertise to make decisions concerning the research design. This group however gave feedback on the community engagement approach by suggesting that meetings should be held with school management committees and PTAs to inform them about the research project. The rationale for the meetings was that parents needed to be aware of what was happening in the schools and that they needed to understand the research and how it will benefit their children. This feedback was used by the researchers because they knew that this stakeholder group had the power to allow the research to be conducted in schools. On the other hand, views of parents did not feedback into the community engagement plan or the research design while views of children who were the targeted study participants were not sought probably because they were considered as less powerful or less knowledgeable in this setting. This case study suggests that power differences between research staff and stakeholder groups due to scientific knowledge determined how stakeholder groups responded to community engagement activities and which feedback to incorporate. As such, the hierarchical, authoritarian and clientship political culture in Malawi (Gaynor, 2011) encouraged deficit models of engagement rather than participatory governance ideals required in collaborative partnerships.

Responding to diverse feedback across research stakeholders in hierarchical power structures however presented challenges to researchers on which feedback to use. Even though the PEAs suggested that meetings should be held with parents in all the participating schools, four out of the seven PTA committees offered contradictory advice. These PTA committees comprised of teachers and parents who were responsible for making some decisions concerning a specific school. The four PTA committees (Chilobwe, HHI, Ndirande and Kanjedza) did not want to conduct meetings with parents and guardians because they thought the communities were already exposed to research and that they generally consented to

participate. Others feared that some people may influence other meeting attendees to refuse to participate in the research which may affect study recruitment. Considering that this stakeholder group had the power to make decisions concerning specific primary schools, their advice was used by the research staff to change the community engagement plan and not conduct of research. This experience however presented challenges to the research staff on whether to incorporate feedback from the PEAs who had authority over clusters of schools or PTAs who had authority over a specific school. Such complex power relations at PEA and PTA levels therefore presented challenges to attain true participatory processes and accountability among different actors. Out of the two school communities that were selected for this ethnographic study, a meeting was organised by the research team to inform parents about the study in South Lunzu but not in Ndirande following advice from the PTAs. In practice, the research team indicated that they experienced fewer challenges in recruiting study participants from both sites. There were however misunderstandings about the research projects particularly in South Lunzu where a meeting was held with parents and this has been discussed in section 7.2.2.

More broadly, this example shows that an interrelationship of visible and invisible power relations at different levels in the organisational hierarchies shaped community engagement processes. In addition, advice from community representatives played an instrumental role by perpetuating deficit models of informing communities rather than engaging them as collaborators. While I have shown that power relations due to organizational hierarchies and scientific knowledge influenced community engagement processes, some research practices also transformed social relations among community members which consequently affected engagement processes. In the next section, I will discuss effects of evolving social relations between research volunteers, researchers and community on community engagement.

Thereafter, I will discuss how conflicting interests of researchers and research volunteers affected the effectiveness of the community engagement approach.

5.3.6 Effects of research practices on social relations and community engagement

Research volunteers were engaged in research to facilitate community participation. In the rural case study, health animators were engaged in the study to train other community members and to facilitate implementation of interventions. In addition, village committee members were also selected in each village to assist with implementation of the interventions. I will be referring to the health animators and committee members as research volunteers. I will present how evolving social relations between research volunteers, community leaders and community members affected community engagement in the rural case study.

As previously explained in chapter three, the system of designating powers to local chiefs to preserve social order and ensure compliance to government regulations was introduced during the colonial period (Ross, 2009). To date, the geographical locations in rural settings where this study was conducted were headed by village leaders or chiefs [*mfumu*]. Service providers including research institutions approached these village leaders to select volunteers to help communicate or implement a particular project. The selection criterion for these volunteers was defined by service providers and 'literacy' was normally a requirement. The research volunteers were residents in the research communities who were either appointed by community leaders or elected by community members.

Despite attempts to engage research volunteers to facilitate study implementation, positive social relations between research volunteers and community leaders were critical to their mediating roles in research. Both researchers and community members supported democratic elections of research volunteers in order to avoid village leaders bias in selecting their clansmen to fill positions in various committees. According to community members, they

saw democratic elections as a means that promoted equitable access to resources from service providers. Even though the communities supported the idea of involving them in the selection process, positive social relations between community leaders and research volunteers in these settings was seen to affect the effectiveness of the community engagement approach to facilitate study implementation.

The provision of training, monetary allowances and other resources to research volunteers created disparities between research volunteers, community members and community leaders which consequently transformed their social relations. As stipulated in the study protocol, the researchers trained the research volunteers on various aspects of the trial in order for them to teach fellow community members. During the training for trainers' workshops, the researchers also provided monetary allowances for transport, meals and accommodation. In addition, the research volunteers received bicycles to assist them with transportation in the villages. The acquisition of financial and material incentives from researchers however introduced tensions in one of the villages because the community leaders became resentful with the research volunteers for receiving financial and material incentives from the researchers. Consequently, the village leaders stopped supporting research volunteers to conduct activities in their village and this affected implementation of interventions. For instance, a research volunteer from a rural setting explains how research practices affected social relations between him and the chief in the following quote:

> *'...At first our relationship [with the chief] was better, but somewhere along the way the chief started thinking differently...The chief's advisors went to the chief and were like "chief, what did the child [research volunteer] give you after attending the training? Aaa! There is nothing that he has given me. He is eating your money while you are in this village!"...eventually the chief started saying "aa! I am not seeing you*

well, when you go to attend the trainings you are not doing anything"...That's when we realised things were not well with our chief too...'

Male research volunteer, rural setting- SSI 008 focal area Y

This quote shows that social relations between the chief and the research volunteer were affected because the chief felt that he was not benefiting from the money that the research volunteer was receiving after attending trainings. More broadly, the authoritarian and clientship political culture in Malawi (Gaynor, 2011) affected community engagement because the chiefs expected personal benefits to mobilise communities to implement interventions.

Due to the tensions between the research volunteers and community leaders, some of the research volunteers reported that community leaders opted to use their authoritative power to fire the research volunteers. The community leaders were however constrained to exercise this power because the research staff indicated that they could not replace the research volunteers since they had already undergone training. For instance, one of the supervisors of the research volunteers commented: *'The other problem was that an animator would tell us they want to stop serving, so we would sit down with the animator to find out what was wrong so that we discuss with the chief...some chiefs would just come and say aah! I have said it and it's done! I have fired that research volunteer and I will choose another one'...You would then find out that the problem was that the chief was cross with the research volunteer'*

Male research volunteer, rural setting-SSI 005, focal area X

Some community leaders therefore stopped supporting the research volunteers to mobilise community members for research activities due to the tensions between them. The community leaders often used their authoritative power to encourage attendance in community meetings and to ensure compliance to interventions. As a result, community

participation in the interventions was poor because community members listened to community leaders over research volunteers. These findings therefore suggest that tensions between research volunteers and community leaders in this authoritarian setting affected community participation in the interventions.

Similarly, FGD participants in the same community stated that some community members became resentful with the research volunteers and shunned the interventions because the research was seen to benefit the research volunteers only. According to the quantitative data collected by the study team, a higher proportion of households in the village where these issues arose had not improved their houses compared to the rest of the villages suggesting the importance of positive social relations (Personal Communication, MMP stakeholders' workshop February 2017). In the quote below, one of the FGD participants explains how some community members reacted when they were asked to implement the interventions.

> *'Some people used to say, they [research volunteers] received money and ate the money. It is not right that they should come and tell us to close the eaves and yet they ate the money by themselves. They were saying it was hurting them. We tried to explain to them that we are also volunteers and we didn't receive the money. We are just doing this for the sake of developing this village'*
>
> Male research participant, rural setting-FGD 013 Focal area Y

This quote highlights typical views of community members that research volunteers were being paid to mobilise communities to implement the interventions while community members were not given training allowances or incentives for participating in village workshops or interventions. In this case, the research project naively perpetuated jealousy between research volunteers and community members by giving financial and material

incentives to research volunteers. Such inequities therefore led some community members to perceive research practices as unfair and to shun the interventions.

Due to low participation in the interventions, some research volunteers resorted to telling community members that the meetings had been organised by *'aboma'* [government officials] in order to increase attendance at the village workshops and mobilise communities to participate in the interventions. Other research volunteers resorted to telling communities that regular attendees will receive bed nets from the government. These research volunteers may have used these strategies in order to ensure increased coverage of the interventions. These strategies however led to mistrust when community members realised that the research volunteers were telling lies. Instead of mediating communication and rebuilding trust between researchers and community, the research volunteers in this case created more mistrust which affected attendance at the village workshops. For instance, one FGD participant from a rural setting commented:

> *'They used to tell us people from government are coming to write down names, and so people would go in large numbers only to find out that the meeting is being facilitated by the malaria people. "You, how can you tell me [that]? I came there hungry". So, if you tell me again tomorrow that there is a meeting, can you really go? That is why when they inform people about a meeting they say "they are inviting us for the same" [laughing]...so participation at the village workshops shall always be a problem even when there is guest at the meeting, only few people who are really interested to learn will go'*
>
> Male FGD participant, rural setting FGD013, Focal area Y

This may suggest that community members valued community meetings that were seen to benefit them in terms of material assistance rather than knowledge. As such, the research

volunteers intended to encourage community participation in village workshops by telling community members that government officials would be present at the workshops to write down their names for handouts. Such experiences therefore contributed to challenges among research volunteers to negotiate top-down study needs and ensure community participation in the interventions.

On the other hand, these tensions were not reported in the villages in focal area X probably because community leaders were used to collective participation in development projects as explained in section 5.3.4. Some of the research volunteers also claimed that such tensions did not occur where research volunteers had kinship ties with village leaders because the community leaders viewed the project as beneficial to their clansmen. Provision of financial and material benefits to research volunteers in such cases did not transform social relations between research volunteers and community leaders because the community leaders felt they benefited indirectly from the research. This implies that engagement of research volunteers who had kinship ties with community leaders responded to the political culture of clientship where 'engagement of the chief's kinsmen' was seen as essential to support study participation. On the other hand, responding to these social norms of reciprocity may perpetuate village level disparities of power that benefit same elites and support unequal social structures that community engagement is meant to overcome.

5.3.7 Conflicting interests of researchers and research volunteers

Even though the researchers intended to engage research volunteers to facilitate community engagement activities without any pay, the research volunteers expected remuneration for their contribution to the research. Inequalities between the research volunteers and research staff in relation to remuneration and privileges led to resentment and tokenistic involvement in the research. Such inequalities therefore perpetuated views of research as a neo-colonial form of exploiting community members as sources of cheap labour, which affected the

effectiveness of community engagement to facilitate study implementation. Thus, the research project was seen to promote inequalities of power and the community engagement approach did not overcome such inequalities.

Research volunteers were asked to discuss their roles in health research. Almost all the research volunteers stated that they were involved in teaching other community members in addition to other tasks aimed to facilitate implementation of research. As research volunteers, they were expected to conduct weekly village workshops (which later on changed to fortnightly workshops) where they taught other community members about malaria prevention. In addition to this, they also worked alongside other community members to ensure that all the interventions were being implemented. As such, their roles were vital to successful study implementation and the research volunteers perceived their role as a form of employment. Rather than perceiving their role as collaborators in service delivery, their responses indicated that some perceived that their role was to facilitate study implementation as shown in the quotes below:

'My responsibility in this research is to ensure that I encourage people in my village...I am supposed to encourage them so that when research is taking place like this, they have to participate. Yes! I need to encourage people and tell them that no! These things shall assist people here'

Male research volunteer, rural setting SSI008, focal area Y

'Our responsibility is that the organisation expects us to write reports if we conducted village workshops. They want to know how many people turn up for meetings, how many men and women. Have we managed to conduct the required number of village workshops? If we failed, what was the problem? That's what the organisation expects from us, reports....'

Male research volunteer, rural setting SSI005, focal area X

Since the research volunteers were tasked with the responsibility of teaching other community members, they gradually became resentful with researchers for not considering them for remuneration. Employment of paid field workers from their communities also led to more resentment because the research volunteers felt undervalued. Over time, some of the research volunteers stopped organising regular village workshops. Thus, there was limited evidence to show that the community engagement approach led to community ownership or collective participation for community level development benefits. In addition, research staff reported that working relations between research volunteers and research staff begun souring because they perceived their roles as 'research assistants' as shown in the quote below:

> *'Our relations with the animators have been really good even though at times it has soured by issues of money. They say Okay, MMP staff get paid for what we do but they just want us to work [freely] for them. And then they start to see us as more privileged than they are and they think we don't give them the respect they deserve why? Because they have been comparing themselves with the research assistants, they live in the same community but they [research assistants] are riding motor bikes and they are using bicycles. So, they think we value the research assistants more than we value them'*
>
> Frontline worker, rural setting SSI 009

These results show that community engagement is a dynamic process shaped by evolving social and power inequalities between research staff, community leaders, community members and other service providers. In addition, power inequalities between research staff and research volunteers in terms of remuneration and privileges strengthened views of research as a neo-colonial form of exploitation. These results therefore reflect those of

Swidler and Watkins (2009) who questioned the feasibility of engaging volunteers to work without any pay in low income countries.

5.4 Conclusion

In this chapter, I have discussed factors that shaped community's response to the community engagement activities. Firstly, I have attempted to understand interface encounters between researchers, community members, community leaders, research volunteers and other service providers to understand how these influenced community engagement practice. Secondly, I have attempted to understand these interface encounters in light of the ideals in the literature on participatory governance or collaborative partnerships between researchers and community.

Even though ethical guidelines promoted collaborative partnerships, both researchers and community members did not wish to engage in collaborative partnerships. The silent 'rules' of engagement were determined by historical engagement with service providers, power inequalities between multiple research stakeholders, social norms as well as evolving social relations among research stakeholders. As such, ideals in the literature on collaborative partnerships may not be responsive to community's needs due to historical, social and political differences. In addition, lack of community activism for these collaborative ideals raise concerns on how these ethical standards can be successfully implemented if community members are not aware of them or if they do not demand them. The results in this chapter therefore raise important questions on how community engagement ought to balance between bridging research stakeholders' contradictory expectations from engagement as well as adhere to international guidelines on community engagement. The next chapter will focus on ethical issues arising from research stakeholders' contradictory expectations from community engagement and application of international ethical guidelines in research.

Chapter 6: Ethical issues situated between community engagement, study design and implementation

6.0 Introduction

Mr. Gama [pseudonym] is a forty-year-old man who resides in a malaria endemic village in rural Malawi. According to local customs, Mr Gama is a permanent resident in Kaweta village [pseudonym] because his father and their kinsmen were born from that village. Mr Gama lived in Kaweta village for all his life together with his wife and three children.

His village was randomly selected to participate in malaria control interventions which included 'house improvement'. As such, research volunteers approached him to close the eaves of his house and put iron mesh in the windows to prevent mosquitoes from entering the house. According to the religious teachings from his church, he believed that diseases such as malaria and pneumonia came because of disobedience to God and not mosquito bites as presented by scientists. Obedience to God was therefore important to prevent him and his family from malaria rather than closing the windows and eaves. In addition, the climate was already hot and closing the windows would make the heat unbearable inside. He therefore refused to close the windows and eaves of his house because malaria was not the 'biggest concern' in his family. The research volunteers however reported him to the chief who came to threaten him to comply with the research procedures or risk being thrown out of the village. Mr Gama was eventually forced to close the eaves and windows to avoid being expelled from the village. He was however resentful towards the community leader and researchers for forcing him to implement the interventions against his religious values and beliefs.

This story highlights the ethical dilemmas experienced among research participants in authoritarian settings who are coerced to participate in research or health interventions to

comply with orders from community leaders. While community engagement is increasingly promoted in health research to seek buy in from community and improve ethical research practice (Dickert, 2005, Emanuel et al., 2004), community engagement can sometimes facilitate structural coercive participation in research and thereby undermine individual's autonomy. In this thesis, the term individual autonomy refers to '*an individual's moral obligation or capacity to determine ones actions'* in the absence of external manipulative forces (Rhodes, 2010). Structural coercion however refers to '*the ways in which the broader social, economic and political context act upon individuals to compel them to enrol in research*' (Fisher, 2013).This chapter seeks to discuss some of the ethical issues arising from community engagement and study implementation in relation to structural coercion and benefit sharing.

In order to conduct any health research involving human subjects, ethical principles and guidelines have to be followed to respect, protect and empower research participants. Core principles for human subjects protection included in ethical guidelines are: respect for persons, beneficence and justice (The National Commission for the protection of human subjects of biomedical and behavioural research., 1979). The comprehensiveness and relevance of these ethical principles in low-resource settings has however been critiqued because of their focus on rights of individual research participants and not community's interests (Mikesell et al., 2013). As such, a proposal to protect community's interests in health research was made (Mikesell et al., 2013). It was argued that human beings are social beings who exist in a network of others such that an individual's involvement in biomedical research may likely affect the whole community (Callahan, 2012). Likewise, it was also argued that research conducted with research participants in low resource settings presents risks and burdens to participants as well as the community, therefore research must seek to benefit the host community as well as the individuals (Hughes, 2014, Robert, 2012). Ethical guidelines

to protect community's interests in health research were therefore incorporated under community engagement. For instance, ethical guidelines on community engagement from CIOMs state that:

> *'researchers, sponsors, health authorities and relevant institutions should engage potential participants and communities in a meaningful participatory process that involves them in an early and sustained manner in the design, development and implementation, implementation of informed consent processes and monitoring of research and in the dissemination of its results' (Council for International Organisations of Medical Sciences., 2016).*

Much of the literature has focused on ethical issues around protection of human subjects from harm (Kingori et al., 2013, Emanuel et al., 2004, Ross et al., 2010b, Marsh et al., 2010). There are however gaps in the literature on ethical issues arising from research stakeholders' contradictory expectations from community engagement and application of international ethical guidelines in research. In this chapter, I will show overlaps between the ethics of international medical research and community engagement in this setting where there was lack of awareness of ethical principles of health research, limited guidance on community engagement or exposure to participatory processes of engaging communities. Some of the ethical goals of community engagement are to enhance protection of research participants and non-research participants, minimize risks, enhance benefits and legitimacy of the research project (Dickert and Sugarman, 2005). I will therefore use ethical guidelines from CIOMS on community engagement and collaborative partnerships to highlight some of the gaps in the community engagement approaches to enhance protection of community, legitimacy of research and promote mutual benefit sharing. Drawing on theories of neo-colonialism, I will show that application of these ethical guidelines in practice reflect patterns that powerful outsiders should have the moral obligation to determine research benefits and

ensure paternalistic protection of 'vulnerable' populations. In addition, I will show that rather than respecting community needs, views of researchers and participating research communities on research benefits and exploitation differed. As a social scientist, my aim is to contribute towards bioethics by using the ethnographic case studies to 'describe the ways things were and not determine how things ought to be' as suggested by other authors (Hedgecoe, 2004, De Vries et al., 2006). I will therefore start by providing a description of local structures and existing gaps that hinder ethical conduct of research (6.1); mutual benefit sharing and researcher's ethical obligation to respond to host community needs (6.2); and finally, structural coercion in the context of community engagement (6.3).

6.1 Local structures aimed to promote the ethical conduct of research

The three study protocols were developed by both local and international researchers with an aim of improving public health as outlined in ethical guidelines. The study protocols were reviewed by the local ethics review committee (COMREC) to ensure that they adhered to international ethical principles of conducting research involving human subjects which are to respect recruited participants or study communities and enhance beneficence and justice. COMREC had 15 members who were mostly Malawian medical professionals. Nine members were staff from COM, six members were from other institutions and there was only one bioethicist and one lay member. Under representation of bioethicists and lay members in the committee raises questions on whether community concerns were taken into consideration when reviewing study protocols.

After receiving ethical clearance from COMREC and other relevant institutions, principal investigators trained their frontline workers on study protocols and Good Clinical Practice to ensure ethical implementation of research. On the other hand, a majority of people in participating research communities were ignorant of these ethical research guidelines as reported in other settings (Allman and Ditmore, 2011). While ethical guidelines on

collaborative partnerships stress that research staff must have adequate training in research design and ethics (Council for International Organisations of Medical Sciences., 2016), training needs for community partners were not taken into consideration. As a result, research staff presumed the moral obligation of protecting community members from ‘harm’ as defined by outsiders while community members were ignorant of these ethical guidelines which were designed to protect them.

Given that ethical principles on community engagement state that health researchers must *'engage communities in the design, development and implementation of research in a participatory and sustained manner'* (Council for International Organisations of Medical Sciences., 2016), one question that needs to be asked is whether 'ethical' standards should be determined by powerful outsiders to protect less powerful stakeholders (communities) from harm. In addition, imposing these ethical standards on community denies the presumption that individuals have the autonomy to make reasoned judgements to protect themselves from harm. In the next section, I present community priorities in light of the research priorities to illustrate that the researchers and community's judgement of community burdens was different. Thereafter, I discuss ethical dilemmas to respond to community needs as intended by ethical guidelines. Finally, I demonstrate how this disconnect between research priorities and community needs impact on community's perceptions of research benefits.

6.2 Mutual benefit sharing and researchers' ethical obligation to respond to host community needs

The ethical justification of conducting health research on human subjects is to generate new knowledge or improve public health (Council for International Organisations of Medical Sciences., 2016). In order to promote the social and scientific value of research, health related research must be relevant to significant health problems and community priorities. It is however recognised that a majority of people in settings that are affected with health

problems may also be vulnerable to exploitation due to poverty, limited access to health care and illiteracy. As such, researchers must ensure that these vulnerable groups are protected from additional harm (Council for International Organisations of Medical Sciences., 2016). Community involvement in determining research priorities is therefore seen as one of the means of preventing harm, promoting the social value of research as well as mutual benefits among research stakeholders (Council for International Organisations of Medical Sciences., 2016). While it is widely agreed that research must promote social and scientific value, questions have been raised concerning what constitutes fair benefits to communities or which group is entitled to benefit (Hughes, 2014, Lairumbi et al., 2012). In this section, I will discuss the disconnect between researchers and community's perceptions of community needs or burdens. I will be referring to the researchers' perceptions as the 'outsiders' viewpoint while the community members views will be referred to as the 'insiders' viewpoint.

6.2.1 Disconnect between research priorities and community's needs

One of the ethical goals of engaging communities in health research is to enhance ethical legitimacy of the research project by allowing community members to express their views and concerns with proposed research projects (Dickert and Sugarman, 2005). Even though the research projects were implemented in selected communities who were at risk of diseases such as malaria, TB and pneumonia, I noted that most community members did not view these diseases as major problems in their communities. I therefore argue that the research projects did not respond to host community needs and that community engagement did not adequately enhance the legitimacy of the research project.

Ethical guidelines on research involving human subjects require that the site for conducting research should be justified by providing quantitative evidence of a high disease burden (Council for International Organisations of Medical Sciences., 2016). The three research projects were implemented in resource poor settings with poor or limited access to health

services and vulnerable to diseases such as malaria, TB and pneumonia. All the three research projects were therefore in line with research priorities included in the national health research agenda for Malawi which was developed by a selected group of academics and health personnel based on 'quantitative evidence' of health problems. On the other hand, focus group participants were asked to state their community concerns and rank those in order of priority. Divergent community concerns emerged across and within focus groups. Common concerns in the rural setting were: shortages of food, lack of ambulances, long distance to access health facilities, lack of employment and long distance to buy maize. Less popular concerns included: inadequate bed nets, poor road network and malaria. Whereas in the urban setting, the top five priorities raised by focus group participants were: poor health services, lack of clean water, poor sanitation, poverty and shortages of food. Less popular concerns were: lack of bridges and increasing cases of diseases such as diabetes and cancer (See figure 6.1).

This shows that despite existing 'quantitative evidence' that these communities were burdened with diseases, only few FGD participants viewed diseases such as malaria as a concern and none of the FGD participants presented HIV/AIDS, TB and pneumonia as concerns. A similar result has been reported elsewhere in Malawi where only a small proportion of people (2%) perceived HIV/AIDS as a pressing problem that government should address (Swidler and Watkins, 2009). Even though participants admitted that malaria was one of the causes of morbidity and mortality in their setting, some participants did not view malaria as a priority for intervention compared to food insecurity. The quotes below taken from FGDs with men and women from participating research communities highlight this point further:

> *'Our biggest need here is food, right. When we hear that people from the government are coming to write down names concerning maize, that's when we rush to the meetings. When we hear that it's not meant to assist us with food, that's when we*

begin to grumble...We have no food, if we come to a meeting like this it means we have left other chores such as charcoal burning. We will just meet, chat and go and yet we do not have anything to even buy a basin [of flour]. That's why most people do not come to attend the meetings'

Male research participant, rural setting -FGD013

'You can go to the hospital and they test you for malaria and find out that you don't have malaria but you haven't eaten for the past two days...how can you eat when you don't have any food. So, people are becoming sick because they are hungry and when they go to the hospital they find out that they do not have malaria'

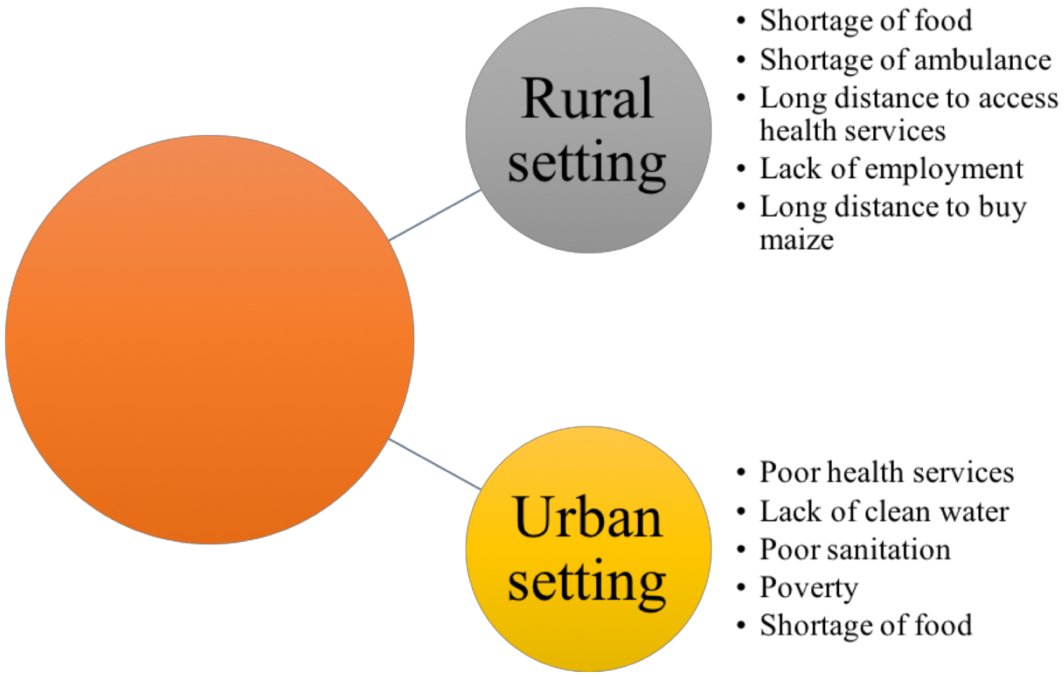
Female research participant, rural setting-FGD015

According to community members, food insecurity was considered a priority because it affected the whole household and led to illnesses while malaria affected individuals occasionally. These results may suggest that malaria and other diseases were not perceived as big burdens to these communities compared to food insecurity. Another possible explanation for this is that there were existing interventions aimed to prevent malaria and they no longer viewed it as a concern. As a result, community members did not prioritize the village workshops because they did not address their immediate physical needs to survive.

In as much as the researchers indicated that community engagement helped to improve mutual learning between researchers and community as indicated in chapter five, responses indicated that residents in these selected villages did not contribute towards determining research priorities probably because the research agenda was predefined by powerful outsiders. One can therefore argue that the research priorities determined by powerful outsiders such as academics and health professionals were not in line with host community needs as they defined themselves.

On the other hand, one may also argue that researchers' judgement of vulnerability or burdens was different from the host communities' judgement. Instead of enhancing the legitimacy of research by engaging communities in participatory processes to identify community concerns, community engagement was used to advance community adoption of professional concerns as well as ethical standards. This disconnect between researchers and community's perceptions of community needs therefore raises questions around 1) the relevance of engaging only a community of academics and health professionals to determine research priorities for host communities and 2) researcher's ethical obligations to respond to community needs.

Figure 6.1: Community concerns in both urban and rural settings



6.2.2 Potential challenges to address complex and dynamic community needs

Given that ethical guidelines state that health research must respond to community needs, the differences in the community concerns across and within FGDs present challenges on researchers' ethical obligations to respond to these diverse needs. For instance, one of the crosscutting concerns pertained to health service delivery. Most of the focus group participants from urban settings indicated challenges and mistrust with public health facilities due to poor services. Participants from urban settings may have perceived public health services as poor probably because they were exposed to quality health services in some private facilities and they compared the services offered. In addition, some FGD participants observed that the elite including legislators, health care workers and researchers who were supposed to improve health services did not access public health services. The following FGD participant from an urban setting articulates this point:

> *'One of my concerns is this, but I don't know how to put it in one word...I don't trust the services that we get [at the public health facility] ...I also don't trust the health care workers because often the people that go there are just poor like us. If you were living here, you would not have been going to Ndirande health facility no! The big officials in the government or politicians do not go there. It makes me think that they either shun public health facilities because the health care workers were not adequately trained or they give us expired drugs'*
>
> Male FGD participant, urban setting- FGD002

This quote is highlighting local community member's disappointments or lack of trust in local elites who were responsible for improving public health services and yet they did not utilize services which they offered. This observation therefore led some community members

to suspect that public health services which were mostly patronized by less privileged community members could potentially harm them.

In contrast, none of the FGD participants from the rural setting perceived public health services as poor. Challenges presented by FGD participants from rural settings pertained to unavailability of a public health facility or lack of ambulances to take patients to a referral hospital. In addition, views of participants across different FGDs in the rural setting differed because some villages were close to a health facility while others were living very far from the health facility. Commenting on health services, one FGD participant from a rural setting said: '*Now there is medication but our concern is the lack of an ambulance because if you are really sick how can you go to Mwanza? The ambulance came but they say there is no driver'* (Female FGD participant, rural setting FGD 009). In contrast, another FGD participant from another village in the rural setting commented: '*Our biggest concern here is the lack of a [primary] health facility ee! Here the health facilities are very far away... we do not fall short of problems but there are certain problems that you are like ee! How can I overcome this problem'* (Male FGD participant, rural setting FGD 013). These findings show divergent community priorities within and across communities which may present ethical dilemmas to researchers to respond to these diverse community needs.

Community priorities also changed over time due to external factors such as climate or presence of other interventions. For instance, there was a drought in 2016 when I was collecting data in the rural case study such that most families were food insecure. During subsequent visits at the field sites, service providers such as the World Food Program were donating food relief items to every household on a monthly basis and community members no longer saw food insecurity as a burden. In the following year in 2017, there was a good harvest in most of the villages. These findings therefore show that community priorities for research or intervention may be too complex and dynamic to predetermine, therefore raising

the question of what should be the researchers' ethical obligation to respond to emerging or dynamic community needs. Challenges to address community's diverse and complex needs have also been reported in the literature on participatory development (Chambers, 1997).

In addition, some community needs were generated during research due to exposure to services offered by the researchers. For instance, the rural case study involved ongoing malaria tests for randomly selected participants to assess the impact of the interventions on incidence of malaria. This created demand for malaria tests to be conducted in the villages because health facilities were far away. Some willing participants who wanted the malaria tests as well as some people who were ill felt the research was not responsive to their needs. Similarly, in the urban case study, the research involved taking a nasal swab and this created a demand of knowing the test outcomes. This raises the question of researchers' ethical obligation to address emerging community demands or community needs and how to address such needs if they are in conflict with scientific procedures or priorities. In the next section, I will discuss differing views of researchers and community members on study benefits.

6.2.3 Researchers and community members diverse perceptions of study benefits

According to ethical guidelines on community engagement, health research should promote equitable benefit sharing by responding to host community needs, making new interventions developed from research available to host community, building local research capacity and improving public health infrastructures (Council for International Organisations of Medical Sciences., 2016, Robert, 2012). Community members however expected to benefit from clinical assessment, treatment, financial and material incentives from researchers. Only few participants mentioned health information, public health benefits and other collective benefits. Since most of the research participants did not view the research projects as relevant to community needs, I noted that their expectations or perceptions of study benefits and

exploitation were shaped by social norms of reciprocity, their socio-economic status as well as a need to maximise research participation to address their needs.

Community perceptions of individual versus public health benefits

Due to poverty, poor health services and probably because the research projects were considered irrelevant to community needs, some research participants particularly in the urban setting indicated that they expected to attain individual benefits such as clinical assessment and financial incentives from research participation. In addition, most of the research participants also viewed research as beneficial if it offered clinical assessment and other material or financial incentives. Research participants motivation to access test results and treatment however must be understood within the socioeconomic context where the research was conducted. Most of the community members in these settings expressed concerns with public health services due to shortages of drugs and staff as shown in section 6.2.1. In addition, the research project was targeting resource poor communities in urban settings who were mostly economically disadvantaged. Most of the research projects at the health facilities offered clinical assessment, treatment, transport reimbursement and other incentives to participating individuals. As such, community members stated that they expected these individual benefits to address their needs for treatment or finances. Examples of how community members discussed research benefits are provided by a mother of a research participant and a female FGD participant in the following two quotes:

'Research helps in various ways...you know a lot about your health and it helps you to access treatment...there is no reason why one should refuse to participate in research...um! People refuse [to participate] out of ignorance...when you are sick they assist you, the assistance you get is better than for someone who is not participating in research'

Mother of a research participant, urban setting- SSI 016

'It's true, some researchers bring their research projects and give out, let's say two tablets of Ufresh [laundry soap that costs less than 20c]. When some people hear that there is a research project and they are giving out soap, they rush...they rush to receive the soap, yes!'

Female FGD participant, urban setting-FGD 001

In the first quote, a mother to a research participant emphasizes that research was beneficial because they accessed better clinical assessment and treatment. According to her, people refused to participate in research because they were ignorant of such 'benefits' of participating in research. In the second quote, a female FGD participant also explains that some people participate in research because of perceived benefits or compensation offered to research participants. This shows that their expectations from research or community engagement were influenced by their socio-economic status and the need to address their needs.

Social norms of reciprocity

In addition, social norms of reciprocity were also seen to inform research participants perceptions of study participation, community engagement and benefits. Most people in both settings relied on social networks for mutual support. For instance, during social events such as funerals or weddings, community members relied on one another by providing financial and material support to the concerned family without being asked to help. In return, the concerned family was expected to reciprocate this gesture to others. Some proverbs were also used to promote values of reciprocating good deeds such as *'lende nkukankhana'* [you rely

on one another to enjoy the swing], *'kachipande ka thelele kamakoma nkuyendelana'* [A plate of okra is best shared by visiting one another]. This communal nature of life, interconnectedness or mutual responsibility towards others is also described as '*umunthu*' or *'ubuntu'* by other authors (Tambulasi R, 2005). Decision making around research participation were sometimes framed around mutual exchanges where participation was supposed to be exchanged with individual benefits. Responses from participants demonstrated that they considered research benefits as fair, if their participation was exchanged with financial benefits, clinical assessment, test results, treatment or health information. Similar results have also been reported in another ethnographic study conducted in Malawi that a gift of soap to survey participants was considered as an entitlement or wage for participating in the survey (Biruk, 2017). Even though the research institution was strengthening local research capacity through capacity building of Malawian staff, community members did not see this as a fair benefit for their participation in research. Failure to respond to these social norms of 'give and take' led to unmet expectations from research participation and community engagement.

Likewise, perceptions of exploitative research were framed around failure to reciprocate research participation with individual benefits. Views of what community members considered as fair benefits or exploitation centred on whether the research participants were properly compensated or paid for their participation in research. More broadly, participants felt research was unfair to poor people because they 'contributed' their samples without experiencing 'visible' benefits while 'visible' outcomes of research benefited affluent researchers. In the following quotes, research participants in the urban setting where there had been several research projects express their views on unequal distribution of research benefits between researchers and community members.

'When information about research is being shared, some people say the ones who are sharing information about research get paid by the government [research institutions] to draw blood. The blood is sold to the government so that they earn their benefits [money]. So, people refuse to let their children participate in research'

Male FGD participant-Urban setting FGD004

'The biggest thing that I see is that, if they [researchers] want to conduct research on flu for example, we just provide them with what they ask from us. But apart from that there is nothing else that we benefit from. If they ask for sputum, we provide them with sputum and they go away. We only participate by providing them with materials for them to conduct research...it's like, those who provide data do not benefit whereas those who conduct the research benefit'

Male FGD participant, Urban setting-FGD 002

These community members felt that research was not beneficial to community because research participants contributed blood and other samples but they were not adequately compensated. On the other hand, researchers got paid for drawing blood from community members. This was viewed as an unfair or exploitative arrangement where researchers earned financial benefits by exchanging research participant's blood with money, while research participants did not benefit financially. These results therefore suggest that the researchers and community members perspectives of study benefits, undue influences and exploitation were contradictory. Most of the research participants enrolled in research to access individual benefits such as treatment and incentives but not for altruistic or public health purposes. This shows that provisions that were defined by outsiders to minimise 'undue influences' were viewed by community members as neo-colonial ways of perpetuating exploitation of community members. These findings therefore raise some insights that issues of 'undue

influences' and 'fair compensation' were not negotiated carefully through community engagement. As such, community engagement did not enhance community benefits as defined by local community members.

Lack of communication

More generally, concerns around research benefits were attributed to absence of communication about study outcomes or lack of appreciation of the impact of research or health interventions on improving health. Concerns around lack of feedback of study findings to participating research communities were raised during community engagement meetings as well as FGDs and SSIs. For instance, during one of the study briefing meetings with parents in South Lunzu, a research staff explained that results were going to be published in a journal which was translated in Chichewa as *'magazine'.* The decision to disseminate results in a peer reviewed journal rather than to communities was probably driven by academic requirements for one to secure promotions and grants. The community leader however enquired why results were going to be published in *'newspapers or magazines'* where most people could not access them or read. This shows that existing channels of communicating research findings through publications were not relevant to participating research communities. Some community members therefore viewed research as not beneficial due to lack of feedback.

There was however a disconnect between researchers and community members perceptions of feedback, study outcomes or research findings. Most of the research participants in the urban case study indicated that they did not see the value of participating in research because the researchers could not give them individual test results. While the researchers often talked about disseminating aggregated results to communities, research participants expected test

results. For instance, one FGD participant from an urban setting where there had been several research projects commented:

> *'The other thing is that aa! We do not really see the benefits of all the research projects that have been taking place. It's like we are just being exploited, they will research and research but they don't tell us the outcomes of the research. That's the disadvantage of research and we can't tell the value of research because they don't tell us the outcomes'*
>
> Male FGD participant, urban setting- FGD006

This shows that the idea of presenting aggregated results for the sake of ensuring anonymity conflicted with research participants needs. On the other hand, the research staff indicated that they could not provide individual test results because most of the research participants could not understand them. This explanation however raises questions on how the intended research benefits were going to be translated to a practical reality if participating research communities were presumed to be incompetent to understand test results. Failure to provide results therefore led research participants to perceive research as not beneficial to the community.

Some participants also viewed research as not beneficial because they felt that health interventions did not eradicate health problems. A possible explanation for this might be that impact of health interventions were not shared with communities and thereby denying them their right to information. For instance, examples were given concerning condoms that they failed to reduce the incidence of HIV/AIDS but rather promoted promiscuity. They also claimed that despite implementing various health interventions to eradicate health problems, community health continued to deteriorate and this affected their trust in the health interventions. As such, some people believed that health interventions were implemented

with hidden motives to infect people with more diseases or reduce their fertility as reported in other African settings (Geissler and Pool, 2006). Part of the resentment with research was because research was conducted among poor communities who could not afford to buy expensive products that were developed as outcomes of research conducted on them. This led people including community leaders to think that research was promoting unequal distribution of research benefits because participating research communities could not access research benefits while researchers attained material benefits. The quotes below provide some insights of how community members discussed the injustices in international research.

> *'According to what I read and hear, some people who are superior think of us poor black people as inferior and as objects for their experiments. They just want to find out certain things and at the end they are the ones to benefit. For instance, a company may fund research on flu in Malawi...They will come to Ndirande to collect the things they need. After 3 to 4 years they will develop drugs to cure flu and it will cost K4, 000 (USD 6) and it ends there. As for you the research participant who contributed a sample, you don't know anything about this and you haven't benefited anything...the ones who provide information like us are not beneficiaries of research'*
>
> Male FGD participant, urban setting- FGD002

> *'ee! We meet a lot of researchers but there is nothing that we see [benefit]. So, we just take it [research] as useless. The ones who come to do the research are the ones who benefit because they couldn't have been conducting research persistently if it did not benefit them'*
>
> Community leader, urban setting-SSI024

In the first quote, the FGD participant indicated that his views concerning exploitative research were influenced by what he has read or heard from other people. Since there were several community based research projects taking place among the low-income populations, this led some people to think that research was conducted on them to test new drugs because they were underprivileged. The increased number of public health challenges in settings where there were several research projects also led some people to think that research did not benefit their communities. Rather, they saw research as promoting unequal distribution of research benefits where public health challenges continued to worsen and researchers benefited by developing drugs that participating research communities could not afford.

Other participants in the urban setting also cited examples of the transitions in drug regimens for treating malaria such as chloroquine, SP and LA as an example of the inconsistencies and ineffectiveness of these health interventions to eradicate health problems such as malaria. Due to the absence of communication, perceived inconsistencies and personal experiences, community members perceived the changes in the interventions as evidence that health interventions failed to eradicate health problems. For instance, one FGD participant stated:

> *'They should do things to ensure that the problem is eradicated for good. When the problem is eradicated they should come with other interventions to help us and not just do things and then leave us in suspense. It's like giving out an injection to cure a certain disease but not being able to treat the disease and then stopping the treatment abruptly'*
>
> Male FGD participant, urban setting-FGD006

In this quote, the FGD participant thinks that the limited time frame allocated for research projects or interventions did not lead to effective eradication of public health challenges. This participant was of the view that research activities and interventions could achieve public

health benefits by focusing on eradicating existing challenges before introducing new research projects or interventions.

Visibility and immediacy of research benefits

In contrast, most of the research participants in the rural case study indicated that they viewed research as beneficial to the community because it empowered them with knowledge of malaria prevention, reduced the mosquito population, reduced cases of malaria and they also received free bed nets and iron mesh. A majority of research participants claimed that they did not know the causes of malaria before the research project. As such, certain signs and symptoms of malaria such as convulsions and seizures were interpreted as witchcraft and therefore warranted treatment from traditional healers. The research project therefore helped them to know causes, prevention and treatment of malaria. Through the research project, community members also became aware that mosquitoes breed in stagnant water and the need to clear these as a way of preventing malaria. Having implemented all the interventions, community members viewed the research as relevant because they experienced a reduction of mosquito bites and cases of malaria. FGD participants also indicated that benefits of the research project were evident at the health facility because there were few people presenting with illnesses compared to the past as shown in the following quotes:

> *'In the past, we were experiencing frequent illness episodes, the kids were becoming sick and we were also becoming sick. So, having considered/weighed these things [interventions] brought to us, we found that cases of malaria are reducing and that is why we are now more accepting. It's because we now experience fewer cases of malaria among our children'*
>
> Female FGD participant, rural setting-FGD015

'As for me, I think I have seen a big difference. I had a child in 2008 and I went to the hospital almost every month because the child would become unconscious. When the malaria people came to distribute bed nets, iron mesh and we closed our eaves and windows it takes maybe four months without experiencing an illness'

Female FGD participant, rural setting-FGD014

Only few participants however indicated that the research was not beneficial. Again, views of fair research benefits and exploitation among these people centred on financial or material benefits given to research participants versus research volunteers. Such people felt they were not benefiting financially for participating compared to the research volunteers who were facilitating community participation in the projects. This shows that such people valued individual benefits more than collective benefits.

Taken together, these results indicate that community views of study benefits may have been different in the urban and rural case studies due to differences in study design as well as immediacy and visibility of study benefits. Since the rural case study was a community based intervention, community members experienced immediate and visible benefits of implementing the interventions such as: a reduction in mosquito population, less cases of malaria in addition to receiving bed nets and iron mesh. On the other hand, the urban case study required individual participation and study benefits were likely to be experienced in the longer term through development of more effective vaccines. As such, community members could not appreciate any visible or immediate result or benefit in the context of community engagement.

Conflict between ensuring compliance to interventions and respecting participants

On the other hand, conflicting perspectives of benefits and risks of interventions between researchers and community raise some questions on whose perspectives should be taken into consideration in the processes of community engagement. Ethical guidelines on community engagement stress that developing countries should determine whether research or health interventions are acceptable to community's health problems (Council for International Organisations of Medical Sciences., 2016). In the rural case study, the government distributed bed nets to most of the households to prevent them from malaria but most people were using them for unintended purposes. During my field work in the rural setting, I observed that charcoal bags and roofs for houses were fastened using bed nets and thereby presenting challenges on researchers' ethical obligations to ensure compliance to health interventions. Rather than using the bed nets while sleeping, some of the households in neighbouring villages also used the bed nets to cover windows. This made me curious to know if people were indeed using the bed nights when sleeping at night. Almost all the FGD participants indicated that they used bed nets probably because this was the desired behaviour as required by the research staff, health care workers and community leaders. On the other hand, some people in both urban and rural settings stated that sleeping under the bed nets was reducing their sex drive. This led them to become suspicious that the government was putting substances [contraceptives] to reduce their sex drive as a way of reducing the population size. In addition, a majority of FGD participants indicated challenges with the insecticides in the bed nets because it was causing a burning sensation, sneezing and that the nets were making them feel hot. Peoples concerns with the bed nets during FGD and using them for unintended purposes imply that some were not using them. And despite the government's efforts to distribute bed nets to all households in 2015, the proportion of people using bed nets only increased from 53% to 55% between 2014 and 2017 (National Malaria Control Programme

and ICF., 2018). Considering that community members experienced challenges with the bed nets and they identified alternative ways of using them to fish, fasten things and cover windows, should the researchers have an ethical obligation to ensure that communities use the bed nets for public health benefits? On the other hand, if the community members saw that using the bed nets for income generation was more important than preventing themselves from malaria, then why should their judgement of benefits and risks be overridden by researchers' judgement?

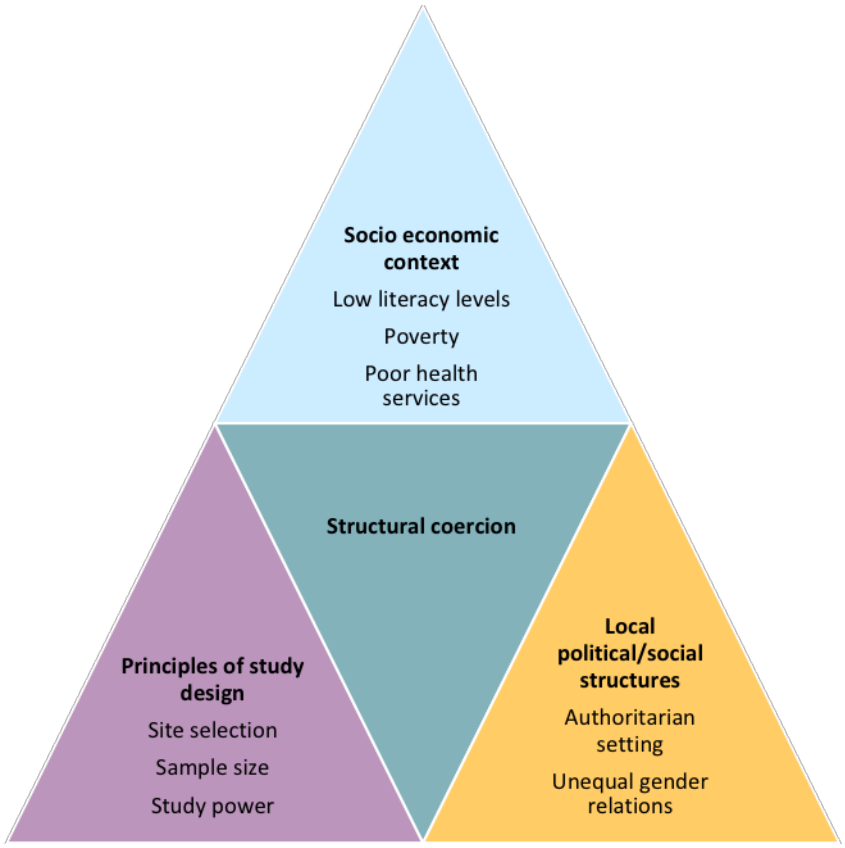
In summary, views of researchers and research participants differed on study benefits and exploitation. While the research staff intended to conduct research for the benefit of communities and to minimise harm, community members particularly in the urban case study did not view the research as beneficial. Their perceptions and expectations from study participation and community engagement were however shaped by their socio-economic statuses and social norms of reciprocity. In addition, lack of communication of study outcomes or impact of interventions also led community members to view research as only beneficial to researchers. On the other hand, some community members in the rural case study viewed research as beneficial because study outcomes were immediate and visible. More generally, these results suggest that the community engagement approach was seen to promote fair benefit sharing in the rural case study because the results were immediate and visible. On the other hand, the community engagement approach did not effectively negotiate views of researchers and community members on research benefits in the urban setting. In the next section, I will discuss the role of community engagement on exacerbating structural coercion.

6.3 Structural coercion in the context of community engagement

While ethical guidelines state that the site for conducting research should be justified by providing quantitative evidence of a high disease burden, conducting health research in these

settings also seems to facilitate structural coercion. Coercion is commonly understood as a direct form or threat of violence; structural coercion however refers to ways in which the broader context compels individuals to enrol in research (Fisher, 2013). Community engagement is promoted in health research conducted in low resource settings to enhance respect and protection of study participants and communities (Dickert, 2005). I will however show challenges with the community engagement approaches to protect communities by focusing on how the social economic context, local political/power structures, social norms as well as scientific requirements for research design compelled some people to participate in research (See figure 6.2). In section 6.2, I discussed how the broader socio-economic context influenced some people to participate in research to address their needs for clinical assessment, treatment, financial and material support. In this section, I will discuss structural coercion in relation to: collaboration with government, engagement of health care workers in research, engagement of community leaders, and social norms in relation to household decision making processes.

Figure 6.2: Interplay of themes that shaped ethical conduct of health research



Collaborations with government

While ethical guidelines on community engagement promote collaborations between researchers and stakeholders such as government and other service providers (Council for International Organisations of Medical Sciences., 2016), such collaborations or links were seen to influence some people to participate in research. As part of their community engagement activities, all the three research projects had links or collaborations with local government. In the urban case study, the researchers sought approval from the Ministry of Education and the District Education Office which gave the impression to some people that the government was involved in implementing the research. Similarly, in the rural case study the researchers collaborated with the District Health Office to implement interventions and this led some people to think that the interventions were being implemented by the

government *[aboma].* The hospital based case study took place at a government hospital which made some people think that the research was part of the health services offered at the hospital. Since most interventions run by the government including vaccinations were mandatory, some people participated in research to ensure that government's interventions succeeded. For instance, one FGD participant from a rural setting commented: *'When researchers approach us, one cannot refuse. You just agree so that things should progress according to the government's intentions '* (Female FGD participant, rural setting-FGD012).

In most cases, the government also worked with community leaders and community health workers to ensure compliance to interventions. For instance, every woman who delivered a baby at home rather than the health facility was asked to pay a goat as a penalty for non-compliance to maternal health interventions. In addition, the government and other external service providers were viewed as powerful actors who facilitated community development to improve the welfare of communities. For instance, the local government and other service providers constructed schools, hospitals, public roads thereby reinforcing the viewpoint that they were instrumental in community development. As previously discussed in chapter five, a common saying in the villages was that outsiders came with new knowledge to make positive contribution. During community meetings, some people including community leaders described research as part of development [*chitukuko*] in their village. As such, this historical background facilitated structural coercion because some individuals participated in research because they perceived research as part of development for the community. Such collaborations between government and researchers therefore compelled some individuals to participate in research out of fear of governments reprimand as reported elsewhere (Graboyes, 2010).

Engagement of health care workers

Misunderstandings on the meaning of research in addition to involvement of health care workers contributed to community members expectations to access clinical assessment and treatment from research. In all the settings, the term 'research' was translated as *'kafukufuku'* in the vernacular language which has a connotation of 'finding out'. Since most of the health researchers were health care workers and the research was either conducted in health facilities or involved clinical procedures, most people had challenges to differentiate between research and clinical assessments. Health researchers were often referred to as *'akafukufuku*' [researchers], *'achipatala'* [people from the hospital] or *'azaumoyo*' [community health workers]. As such, some people particularly in hospital based studies consented to participate in research to access clinical assessment, individual test results and treatment. It is also worth noting that some research projects were providing quality health services to individual research participants as well as their families and hence this led to confusion between research and clinical care. Community member's perceptions of health researchers as health care workers and their expectations of receiving better health services therefore coerced some people to participate in research.

In addition, community's perceptions of health researchers as health care workers exacerbated power imbalances between community members and researchers. As already discussed in chapter three, local people have their own indigenous preventive and healing practices. The introduction of biomedicine during the colonial and post-colonial period presented these as more effective to prevent or cure diseases while discouraging indigenous healing practices as less effective or harmful. Since most of the research projects took place in resource poor communities where knowledge of biomedicine was low, some community members viewed themselves as ignorant and viewed health care workers as people who were knowledgeable. For example, one FGD participant from an urban setting said: '*Malaria comes through*

various ways, we do not know how malaria comes about. The researchers know that malaria comes in this way and for us to prevent or eradicate malaria we need to do this and that...' (Female research participant, urban setting-SSI 015 ND). This shows that some community members perceived these health care workers as experts in bio medicine because they discovered or knew the causes of malaria. As such, they felt they needed to follow instructions from researchers since they knew the causes and cure for malaria. Such perceptions of health care workers as knowledgeable therefore obliged some community members to participate in health research.

Finally, most of the community members including village leaders had challenges to differentiate between research and community services offered by NGO and CBO. During FGDs, participants were asked to state the research projects taking place in their community or at the health facility. Responses to this question included NGOs working in the communities such as: Hunger Project, African Parks, CADECOM, Concern Universal, SOS and World Vision. Both research institutions and NGO were often referred to as *'mabungwe'* in the vernacular language and community members had challenges to differentiate between research objectives and NGO objectives. Due to the confusion between research and NGOs and historical experiences of being aid recipients, some research participants were participating in research with expectations of receiving support from NGOs. Thus, the broader socio-economic context compelled some people to enrol in research with expectations of receiving economic support.

The coercive power of community leaders in authoritarian settings

While involvement of community leaders in research is often considered as culturally appropriate in most African settings (Tindana., 2011), community leaders sometimes used their coercive power to facilitate participation or non-participation. This consequently

undermined an individual's autonomy to participate in research rather than promoted individuals' rights to make autonomous decisions to participate in research.

Since the research was conducted in an authoritarian setting where the community leader was influential, it was acceptable for community leaders in these settings to impose a fine on individuals who did not follow orders or failed to participate in public health interventions. The community leaders ensured compliance by threatening people that they would be thrown out of the village or that they will be restricted from accessing social services. This led some community members to comply to research procedures as shown in the quote below by a female FGD participant: *'Of course, there were a few challenges but the chief used his power and everyone closed their eaves...he was telling people that their mosquitoes would infect others and If they suffer from malaria they should not go to the health facility. So, everyone closed their eaves...'* (Female FGD participant, rural setting-FGD012). The use of coercive power among village leaders therefore coerced some people to participate in research and thereby compromised ethical research.

Likewise, the ethnographic field work from the rural case study showed that community acceptability of malaria control interventions was better in villages where research volunteers had support from community leaders. Attaining high coverage rates was necessary for research purposes to prevent malaria but also desirable when reporting progress during monthly meetings. The community leaders therefore used their social position to influence communities to attend village workshops and participate in the interventions as shown in the following quote: *'Yes, I call for the meetings by myself...I tell them If you don't come to this meeting I will not write down your name for other things relief items'* (Community leader, SSI024 Focal Area X). Since the village leaders were powerful in these settings, their presence and involvement in the activities would influence other community members to participate. Consequently, the community leader’s influence would lead to high coverage

rates. This example highlights overlaps between international research ethics and socially accepted norms of using coercive power to promote participation in public health interventions. Even though engagement of community leaders is recommended in these authoritarian settings, the use of coercive power to influence participation in research is disempowering to individual autonomies. In this case, engagement of community leaders did not effectively protect communities from being coerced to participate in research.

The coercive role of men in household decision making

Collaborative partnerships between researchers and community require recognition and respect for community's values and social practices (Council for International Organisations of Medical Sciences., 2016). Social norms however inadvertently encourage vulnerable groups such as women and children to be coerced to refuse to participate in health interventions.

Decision making in most households was done by men and this has also been reported elsewhere (Kamuya et al., 2017). Responses from FGD participants particularly from urban settings indicated that decisions concerning research participation were made by men or women depending on the type of research, where the research was conducted and who was involved in the research. A majority of female FGD participants felt that they did not need consent from their husbands or partners to participate in qualitative research and other health facility based research involving women because they could make such decisions autonomously. Opinions however differed on research involving children or the entire household because some women felt they needed to involve men in decisions concerning their household while others felt they could make independent decisions as the main caretakers. Some women in the urban setting indicated that they enrolled their children in research to find treatment, but they did not disclose this information to their husbands or partners to prevent conflicts. Both male and female FGD participants reported that in some

cases a partner/husband's knowledge of the woman or child's participation resulted in conflicts or physical violence to force women to withdraw from research as shown in the following quotes: *'You see, there are a lot of research projects that are fine but if the man doesn't understand them very well, you can't continue...The man uses his power as a man to say my child should not be involved in the research. And they threaten to say, if you do this, don't come to my house, and stay right there! and the wife just withdraw'*

Male FGD participant, Urban setting-FGD002,

'Yes, some women have complained that they got beaten by their husbands for participating in research...Some men don't really understand or they are just jealousy and they would report these issues to the chief. In the past, some researchers were giving out nappies, soap or K1, 000 (USD1.20) ...some men would go like aaa! don't I provide these things to you! then they slap the wife....'

Male FGD participant, Urban setting-FGD 004

This shows that social norms could sometimes promote coercion or prevent some women from making autonomous decisions to participate in research out of fear of tensions or physical abuse.

Lack of a man's understanding of the research objectives was often cited as the main reason why some men forced their wives, partners or children to withdraw from research. In addition, some men felt that the women didn't have to participate in research to access items that they could provide. In both urban and rural settings, I noted that most of the workshop participants or meeting attendees were mostly women which meant that men were not being reached with the study information. Monthly reports from research volunteers in the rural case study also confirmed that most of the workshop participants were women rather than

men. One of the reasons cited by FGD participants why few men participated in village workshops was that they engaged in seasonal jobs or income generating activities to provide for their families. This finding however contradicts previous observations where women's participation in development committees was low due to logistical constraints (Cornwall, 2000). The increasing number of women's participation in village workshops in this rural setting could also mean that the women responded out of submission to authorities which is ingrained in the Malawian culture (Walsh, 2018).

Since it was socially acceptable for men to make decisions concerning their households and for women to be submissive, this presented ethical dilemmas around respecting individual autonomies of women and children and consequently protect them from exclusion. While women in the urban case study indicated that they could easily conceal the child's participation in research from their partners, some women in the rural setting had challenges to implement the malaria control interventions such as iron mesh and bed nets because of their partners influence. For instance, some FGD participants gave an example of a certain man who removed iron mesh from his house after the wife had consented. Talking about this issue, some FGD participants from both settings commented:

'At the time when we were giving out the iron mesh, there was a certain village where the man said we should not put the iron mesh at his house. Thereafter the wife approached us that we should go and put the iron mesh. That same day the husband removed the iron mesh and sold it, because he did not want the iron mesh at his house...we don't know what he was thinking'

Male FGD participant, rural setting FGD 010

'Yes, a woman alone can't decide without the approval of a man, it's impossible. But if the man gives his views and you have agreed on one thing, that's when a woman finds the power (courage) to go and consent to participate...but without the husband's approval, it can't happen'

Female FGD participant, urban setting FGD003

Overall, these results indicate that community engagement approaches did not effectively take into consideration social norms that may undermine individual's autonomy and affect ethical conduct of research. Despite the increasing number of women participating in village workshops, the women did not always voice their challenges to use the interventions due to their husbands influence.

Taken together, these results show that low research literacy, social norms, local power structures, poverty as well as the need to access test results or treatment led to structural coercion. While community engagement is promoted to improve ethical research practice, I have shown contextual factors that affected individuals to make autonomous decisions to participate in research. These included: collaborations with government, engagement of health workers, the coercive power of community leaders and men. Community engagement alone did not address underlying structural inequalities of power or gender or minimise the effects of poverty, poor health services and ill health on structural coercion or protected research participants' autonomy. In addition, community engagement did not mitigate the impact of these structural factors on research participation, thereby rendering the notion of voluntary or altruistic participation questionable (Kingori, 2015).

6.4 Conclusion

In conclusion, this chapter has highlighted some of the gaps in community engagement approaches to ensure adequate protection of community members. Despite ethical guidance

on community engagement to improve the relevance of research to host communities, I have shown that views of researchers and community members differed on community needs and research priorities. Community needs also varied within as well as across groups raising questions on researchers' ethical obligations to respond to these diverse needs. Since the research priorities were not considered as relevant by community members, views of research benefits and exploitation also differed between researchers and community members. Most of the research participants enrolled in research to access individual benefits rather than collective benefits. Apart from community engagement, the broader socio-economic context, low research literacy, social norms and local power structures were seen to present structural coercion. As such, the community engagement approaches did not adequately protect communities from being unduly influenced to participate in research nor promoted fair benefit sharing. Rather, community engagement practices were used to legitimize the research and facilitate community adoption of concerns and ethical standards as determined by powerful outsiders.

These findings demonstrated that an interplay between social norms, power inequalities, socio-economic factors and scientific requirements for study design influenced ethical conduct of research. Since guidelines on community engagement stress that communities should be involved in determining research priorities, one question that needs to be asked is whether ethical standards or research benefits should be imposed on communities. These results also raise important questions on how to balance using community engagement to improve study participation, minimise coercion and ensure 'voluntariness' in informed consent. Having discussed ethical issues arising from community engagement and study participation, the next chapter will focus on outcomes of community engagement on study acceptability.

Chapter 7: *'Beginning to embrace researchers stories':* knowledge re-production and study acceptability in the context of community engagement

7.0 Introduction

As part of community engagement activities, research staff from the urban case study planned to have a series of meetings with stakeholders to inform them about the study. The first meeting was held with officials from the District Education office from Blantyre district. I therefore accompanied the research staff to the stakeholder's meeting as an observer participant.

At the meeting, the research staff explained the aims of the study, how the seven public school communities were selected to participate in the research, the research procedures and intended study benefits. In response, the District Education Officials sought clarity on some of the issues raised in the presentation. They also stressed the importance of having community meetings to ensure that the community understand the research objectives and prevent bad rumours. In order to illustrate the importance of having community meetings, an example was given of a mass intervention by the government involving schistosomiasis medication. The officials explained that the Ministry of Health had written letters to parents and guardians of children in public schools to inform them about the intervention. Thereafter, the children were asked to take the medication at the schools but unfortunately some children fainted after taking the medication. According to the officials, this led to bad rumours in the community that the school porridge was making the children faint or that the medicine was designed to make the children faint. Interestingly, rumours concerning the schistosomiasis intervention were frequently cited in subsequent meetings across different settings. As a

result, this negative experience led some parents to discourage their children from participating in research and other health interventions.

It was however surprising to me that despite the school communities being far apart and loose knit, most people had heard about this rumour and they believed it. In contrast, none of the FGD participants in the rural setting where people were close knit mentioned this incident. This made me curious as to how community members communicated among themselves, why this experience of the schistosomiasis intervention was interpreted as having malicious intentions in urban settings, why the local interpretation of the schistosomiasis intervention was more popular than the scientific explanation. Finally, I was interested in finding out how did community engagement or study practices impact on individuals' agency to make informed decisions or improve study acceptability.

As previously discussed in chapter five, community engagement was used in the research projects to improve informed participation and study acceptability. As such, the community engagement activities reflected deficit models of engagement because researchers used one way communication to inform communities about the research projects. I also indicated in chapter six that despite informing communities to improve informed participation, community engagement approaches in some cases presented ethical dilemmas around respecting individuals autonomies. In this chapter, I aim to use the three case studies to discuss the outcomes of community engagement on knowledge re-production and agency. In addition, I aim to discuss broader contextual factors that challenge assumptions that deficit models of increasing knowledge of research lead to increased participation, minimize rumours or promote study acceptability.

Models of engaging communities to increase understanding have been critiqued by some scholars as 'deficit models' because of the assumption that communities are ignorant and they

need to be educated or informed (Bauer et al., 2007). As a result, new recommendations published in the 'Science and Technology' report in 2000 were to improve dialogue between scientists and publics in the early stages of scientific projects with an aim of rebuilding trust, improving the quality and relevance of scientific projects (House of Lords, 2000). This collaborative approach in which lay people are involved as equal partners or active agents in the production of scientific knowledge was therefore called 'co-production' of knowledge (Heaton et al., 2016).

In the three ethnographic case studies, neither the researchers nor communities intended to be involved in co-producing bio-medical knowledge. However, as researchers communicated bio-medical knowledge to community members, this knowledge was reproduced and led to new ideas or hybrid knowledge which impacted on their agency. A previous study has explored how this blending of bio-medical knowledge and indigenous knowledge or ‘medical syncretism’ impacts on treatment seeking behaviour (Muela et al., 2002). In this chapter, I discuss how this medical syncretism or hybrid knowledge impacts on research participation or resistance. According to Foucault, as institutions exert power on groups or individuals, this may generate resistance to the effects of power (Balan Sergiu, No date). Resistance may therefore manifest through passive forms such as non-corporation, silence, escapade, avoidance and deception and not necessarily violent confrontations (Lupton, 1997). Such forms of resistance may also be masked with symbolic conformity and are considered as weapons of powerless groups (Scott, 1997). I define bio-medical knowledge as the knowledge generated through empirical work or widely accepted principles within scientific communities. Local knowledge will be defined as the knowledge held by most people in a community based on experiences, cultural values and beliefs, while hybrid knowledge will be defined as the knowledge which is informed by a mix of bio-medical and local knowledge or previous experiences with health services.

Many studies have reported community concerns with power inequalities in health research that researchers steal or draw blood for evil purposes to enrich themselves (Geissler and Pool, 2006, Fairhead et al., 2006, Graboyes, 2010, Marsh et al., 2008a, Mfutso-Bengo et al., 2008a). These concerns have however been dismissed as rumours by researchers and attributed to ignorance, low research literacy or superstition. Community engagement is therefore used in these settings to increase understanding of research objectives and study acceptability. Few studies have however looked at the mutual influence of bio-medical knowledge and local knowledge on knowledge re-production in communities as well as research participants agency. This chapter seeks to contribute to these knowledge gaps. I will therefore start by discussing pre-existing or indigenous communication approaches (7.1), outcomes of community engagement on community understanding of research (7.2) and finally discuss community engagement, knowledge re-production and study acceptability (7.3).

7.1 Pre-existing or indigenous communication approaches

Communities in both settings relied on verbal communication, however residents in the urban setting had increased exposure to more channels of communication. In the rural setting, community leaders as well as service providers often used oral communication to relay information to communities. For instance, community leaders used to send some men to move around the village at night to invite people to an upcoming community meeting. In response to the chief's invitation, the villagers came to the chief's house or to a tree shade [*mkesha*] where they normally conducted meetings. Since most of the people in this setting were farmers or operated small businesses, they could easily find time to attend community meetings. Shunning these meetings without sending an apology also attracted penalties in some villages. As such, these self-organised community meetings provided a platform to share information because attendance was usually high.

In contrast, community members in urban settings had increased exposure to information through mass media. Most of the people from urban communities had migrated to urban locations in search of employment or business opportunities. A higher proportion of residents in urban settings also had increased access to information through radio, television, newspapers, internet and other forms of media. Attendance at community meetings was a challenge because most people went to work or businesses.

A collectivist culture was notable in both settings because people relied on mutual support from other community members and collectively participated in certain activities of interest. I define individualism as the '*focus on the self as a unique entity'* while collectivism will be defined as '*the focus on the self-embedded in group membership'* (Gudykunst et al., 1996). In the rural setting, many people were familiar with one another because they shared family ties or they grew up together in the same villages. Since community members were closely knit, they walked together to their gardens, markets, clinics, maize mill, water well or forest to fetch firewood. Issues related to health, marriage and other events that took place in the village were discussed when people gathered together. Information in the villages therefore circulated through word of mouth and most people trusted information accessed within their immediate social networks.

Due to urbanisation, there was a mix of both individualist and collectivist cultures in urban settings. Communities in the urban settings were generally loose knit. However, individuals who resided in the same geographical location; or with shared interests; or similarities in terms of tribe, religion, profession also relied on other community members for mutual support. In the settings where research was conducted, population densities were also high and most people lived in close proximity. People living in close proximity therefore collectively participated in some activities as neighbours or members of community groups.

Common to residents in both urban and rural settings, most people relied on social capital or practiced *umunthu* during illnesses, funerals and other social events and this has also been noted elsewhere (Anders, 2002). I define social capital as the networks of relationships among people, with norms of reciprocity, that enables members of the network to act together effectively to pursue shared objectives (Field, 2003). For instance, if one member of the network was sick and admitted to a hospital, the women prepared food and visited the sick person as a group. During weddings, initiation ceremonies and funerals, neighbours or friends also supported the concerned family with food, transport, money and other forms of assistance. It was socially expected that families would reciprocate the assistance given to them by supporting others in times of need. Failure to support other families during critical moments led to lack of support from other community members. Most people in urban settings therefore joined various community groups to expand their social capital because this was useful for business transactions as well as social support during critical moments. In the following section, I will discuss outcomes of community engagement approaches used in the different case studies on community understanding of research.

7.2 Community engagement and community understanding of research objectives

The urban case study used community meetings and written documents to communicate study information and invite individuals to participate in research. While the rural case study trained community members to teach other community members to encourage community participation in interventions. Both researchers and community members acknowledged communication challenges between them. Research staff attributed community's lack of understanding of research to illiteracy whereas communities attributed them to absence of or poor communication.

In the two community based studies, I observed that community members in the rural setting where literacy levels were very low (49%) demonstrated better understanding of study

objectives compared to community members in the urban setting where literacy levels were higher (72%) (National Statistics Office., 2012) as it will be shown in subsequent paragraphs. In addition, research staff in the urban setting claimed that a majority of research participants with higher education levels declined to participate in research. This shows that illiteracy was not the only factor that led to limited understanding of study objectives or refusals. In this section, I will discuss the community engagement approaches used in the urban and rural case studies in light of pre-existing communication and sociocultural norms across the urban and rural contexts.

7.2.1 Peer education in a rural context

The rural case study required collective participation of community members in the interventions. The community engagement approach and the study requirements to collectively implement the interventions therefore fitted well with pre-existing communication and sociocultural norms in rural contexts. In the rural case study, village workshops were conducted every fortnight to teach communities about malaria control interventions and to facilitate community participation in the interventions. Since communities in this setting normally accessed information through community meetings, having regular village workshops may have fitted into pre-existent communication approaches and contributed to better understanding of the study objectives through regular reinforcement of the messages. In addition, many people in this setting were long-term residents, close knit and usually available during community meetings because they were mostly farmers. These factors made it possible to conduct village workshops and facilitated better understanding of the research objectives.

Since communities relied on verbal information from their social networks, engagement of local people improved access to information because research volunteers were residents in the villages. Engaging research volunteers who were part of the community also enhanced

discussions of the study information during village workshops and beyond. This may have contributed to spread information about the study beyond people who regularly attended the workshops. Community members were also more likely to hear and discuss the study information from their social networks even if they missed meetings as shown in the following quote:

Interviewer: *So, how do you know about all these issues and yet you do not attend village workshops?*

PF: *I just learn them from other people*

Female community member, primary education, rural setting-SSI 001

Interviewer: *Okay, so how do you look at the communication approaches used by the researchers?*

PM: *I found their approach good because the people approached me directly and I was chatting with them in the same way that I am chatting with you and so they explained. I did not just hear rumours that iii! They passed by here and it was like this or that, they came here and that's why we begun to embrace their stories*

Female research participant, No education, rural setting-SSI003

These two quotes show that using peer education facilitated community understanding of the interventions because it fitted with communication norms. Most of the community members understood the research objectives even though they did not always attend village workshops

or engaged in the interventions. More generally, community participation in village workshops and interventions such as larval source management fitted with social norms of collective participation.

7.2.2 Community meetings in an urban context

In contrast, information about the urban case study may not have been understood properly because the community engagement approach did not fit well with pre-existing communication approaches. The urban case study required individual participation in the surveys. Community engagement meetings took place only once to inform communities about the study while written study information were sent to randomly selected parents to inform them about the study and to invite children to participate. I however noted that attendance of parents at sensitization meetings was poor in comparison to the number of children attending the schools. Most of the parents reported challenges in attending community meetings due to other competing activities such as employment, businesses and other social activities. In addition, residents in urban settings had increased exposure to information through other sources of media and community meetings may not have been an ideal approach for communication in this setting. While sending study information sheets to parents in the urban case study was generally considered as an effective and convenient means of communicating, this approach did not seem to improve research participants understanding of the study objectives. Although the parents were informed about the research, many participants still had misconceptions about its purpose and they participated in the research to know their test results as shown in the following quote:

> *'I understood that there are certain diseases that come from the nose or mucus, so I thought that ummm! We have been privileged because our child has been selected [to participate in the research] which is good because my whole family is going to know whether we have the disease [pneumococcal diseases] or not'*

Father of a research participant, primary education, urban setting-SSI013

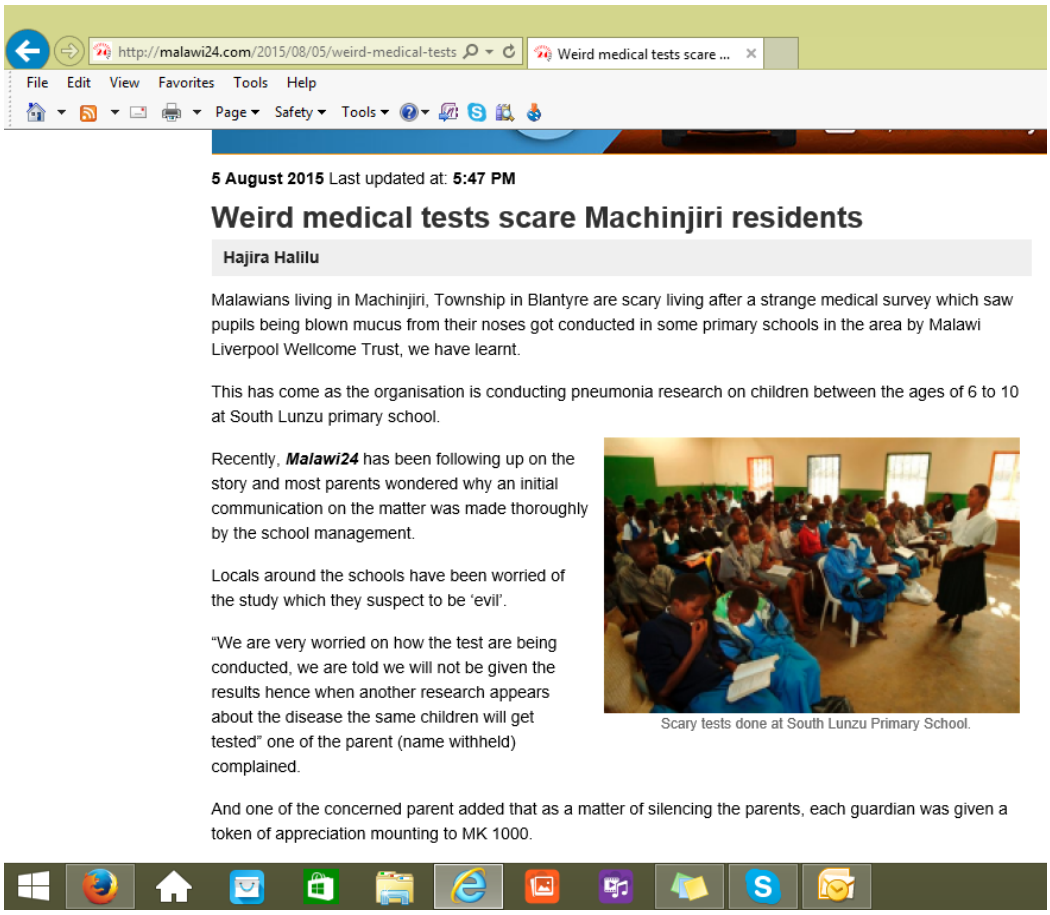
This quote shows that the father to the research participant did not understand the research objectives. He was glad to have his child participate in research because he thought the researchers would provide them with a diagnosis of whether the child had pneumococcal diseases or not. The researchers however were interested in aggregated results on the prevalence of pneumococcal diseases.

In addition, two divergent discourses also emerged during SSIs with parents in relation to written information. One parent demonstrated that the letters gave an impression that the child was privileged to be selected for participation while other parents felt they needed verbal information to make an informed decision. For instance, there was a sense of urgency in a parent to act on the letter as shown below: '*Mmmm! sending letters [study information sheets] is a good approach. Since the letter was sent to my home, I just needed to follow what the letter says...I came because I received the letter'* (Mother of a research participant, no education, urban setting-SSI010). These views also surfaced through informal conversations with some children who indicated that they did not give the letters to parents because written communication would make some parents force their children to participate in research. It is therefore likely that written information from schools potentially gave an impression to some parents that participation in research was mandatory since participation in school activities was often mandatory. In addition, some of the parents decided to meet the research staff to understand fully about the research even after reading the letter. For instance, one mother said: '*When the letter was read, I understood, but I decided to come and listen to them face to face from the mouth of the person who sent the letter'* (Mother of a research participant, primary education, urban setting -SSI012). Another parent indicated that she refused to allow her child to participate in the research because the child explained that the researchers will draw blood even though she read that they will not draw blood. This shows that despite

reading the study information, the mother made a decision based on her previous experience with research and verbal information from the child. Together, these results provide important insights that the use of written information gave an impression that participation was mandatory and it did not always lead to informed participation.

In addition, misconceptions and rumours about the study still arose, despite using community engagement to improve community understanding of the research. For instance, during the course of the study an internet based article was published indicating that "weird medical tests" were being conducted among school going children in one of the townships (See figure 7.1). The article also indicated that the research project was evil and that they were drawing mucus from children and silencing them by giving them MK1, 000 (US$1.25). It is worth noting that, medical procedures such as nasal swabs were usually performed in health facilities rather than classrooms. As such, taking nasal swabs among school children in a classroom was perceived as 'weird'. In addition, there were also many rumours circulating in the communities that research was evil. Their interpretation of the research procedures was therefore built on their previous experiences of medical procedures being conducted in health facilities, local beliefs and absence of study teams at the school to respond to community concerns. Overall, these results suggest that misconceptions or rumours about a study may arise if communities are not properly informed about research objectives. More broadly, these results challenge the ideals of using community engagement approaches that do not fit with pre-existing communication approaches, and social norms to improve informed decision making. In the next section, I will discuss knowledge re-production in the context of community engagement and consequent effects on research participants agency and study acceptability.

Figure 7.1: Internet based article on urban case study



http://malawi24.com/2015/08/05/weird-medical-tests

Weird medical tests scare ...

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5 August 2015 Last updated at: **5:47 PM**

Weird medical tests scare Machinjiri residents

Hajira Halilu

Malawians living in Machinjiri, Township in Blantyre are scary living after a strange medical survey which saw pupils being blown mucus from their noses got conducted in some primary schools in the area by Malawi Liverpool Wellcome Trust, we have learnt.

This has come as the organisation is conducting pneumonia research on children between the ages of 6 to 10 at South Lunzu primary school.

Recently, ***Malawi24*** has been following up on the story and most parents wondered why an initial communication on the matter was made thoroughly by the school management.

Locals around the schools have been worried of the study which they suspect to be 'evil'.

"We are very worried on how the test are being conducted, we are told we will not be given the results hence when another research appears about the disease the same children will get tested" one of the parent (name withheld) complained.

Scary tests done at South Lunzu Primary School.

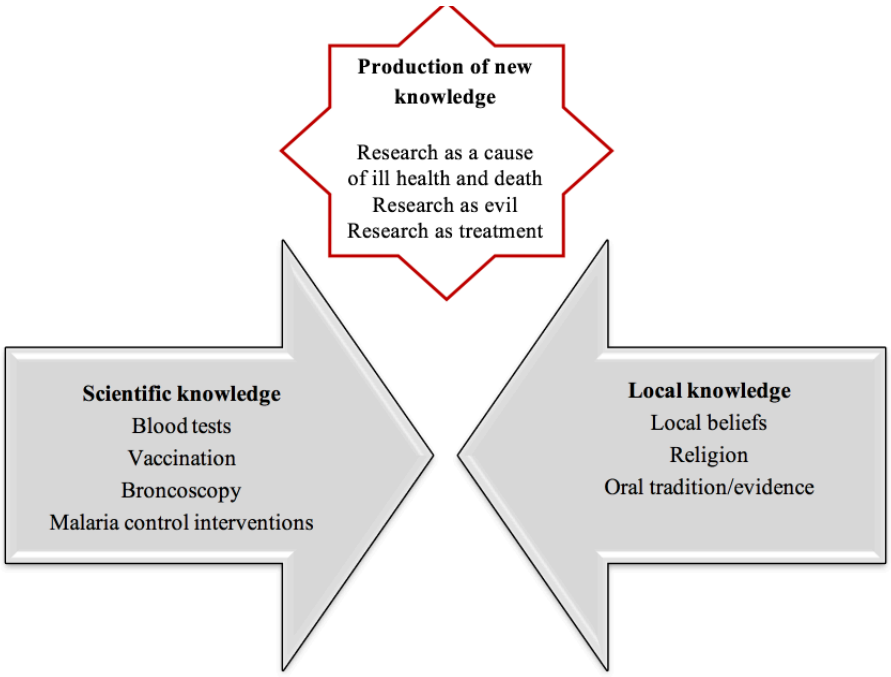
And one of the concerned parent added that as a matter of silencing the parents, each guardian was given a token of appreciation mounting to MK 1000.

7.3 Effects of historical experiences on agency in community based studies

Apart from ineffective communication, decision making around research participation or adoption of interventions was informed by previous and current experiences with health research, as well as influences of other people within social networks. Reasons that led to non-participation in research were therefore not entirely due to illiteracy but informed by a mix of both bio-medical and local knowledge as well as their lived experiences and lay interpretations of specific research procedures. In chapter six, I indicated that power inequalities between researchers and communities presented structural coercion to research participants and this has also been reported elsewhere (Kingori, 2015). In this section, I will discuss outcomes of research practices on knowledge re-production and research participants choices to consent or refuse to participate in research. I will therefore refer to research

participants choices to consent or refuse to participate in research as agency. According to Bandura, '*agency refers to acts done intentionally'* (Bandura, 2005). I will therefore describe effects of research practices on knowledge reproduction in the communities and research participants agency. Thereafter I will discuss how community's reliance on social capital influenced study acceptability.

Figure 7.2: Interface between bio-medical knowledge and local knowledge



As previously discussed, community members historical experiences with other interventions and the mismatch between 'promised health benefits' and lived experiences were seen to impact on decision making in research. In urban settings, some community members suspected that researchers only communicated the positive aspects of an intervention to encourage participation without disclosing ill effects. The most frequently cited example concerned a mass intervention by the Ministry of Health discussed in the introduction of this

chapter where school going children were given schistosomiasis medication. Letters were sent to parents to inform them that children will be given the medication without disclosing the side effects. However, many students fainted after taking the medication. In the absence of an explanation from the Ministry of Health officials about the side effects experienced by the children, some parents thought that the medication were meant to harm their children rather than to improve their health. Since there were many rumours in relation to malicious intentions of health interventions, they suspected that children fainted due to the medication or the school porridge. Following this, individual stories of children who fainted spread widely and became well-known in most of the school communities. These stories were reinterpreted alongside pre-existing rumours that the government intended to reduce the country's population growth by inducing contraceptives in subtle ways. Rumours therefore begun to spread that Ministry of Health was giving out the medication to make children infertile and reduce population growth. As a result, some parents discouraged their children from taking the school porridge which aimed to improve their nutritional status. Other parents discouraged children from participating in health interventions and this experience impacted on research participant's agency in the urban case study. This shows that information alone through community engagement did not effectively improve informed participation in research but rather historical experiences with health interventions shaped research participants choices to resist research activities.

While the 'schistosomiasis mass intervention' experience was raised in most of the FGDs in urban settings, none of the FGD participants in rural settings mentioned this issue. A possible explanation could be that community members in over researched communities in urban settings interpreted the intervention as having ill intentions based on pre-existing experiences or rumours concerning health research or interventions. Community members in the rural setting may not have attributed the fainting to the medication because they had limited

experience with research, or they may have attributed the fainting to other factors such as hunger.

7.3.1 'Hybrid knowledge'; as an outcome and a barrier to community participation

Even though community engagement was used to improve informed participation, as researchers communicated bio-medical information, this resulted into new ideas or 'hybrid knowledge' informed by both bio-medical and local knowledge or entirely based on lay interpretations of research procedures (See figure 7.2). Since personal agency functions within a broad network of socio-structural influences (Bandura, 2005), these new ideas or 'hybrid knowledge' therefore circulated within social networks in the communities and may have affected research participants choices.

A classic example to demonstrate effects of knowledge re-production on community resistance pertained to a long-standing issue around drawing blood for research purposes. Concerns around *'kupopa magazi'* [drawing blood] were widespread in both urban and rural settings and these have also been widely reported elsewhere across Sub Saharan African countries (Geissler et al., 2008, Fairhead et al., 2006, Graboyes, 2010, Ashforth, 2014). These concerns were informed by a mix of both local and bio-medical knowledge and became widely accepted in the communities.

The frequency of drawing blood on the same individuals, amount of blood samples, lack of feedback on test results and general lack of understanding of the intended use of the blood led to production of 'hybrid knowledge' which affected the acceptability of research projects. Since most of the research projects involved drawing blood from sick people, some community members attributed ill health or death of a research participant to depletion of blood in the body. For instance, at one school there was a story circulating in the community about a research participant who died while being followed up by researchers at their home.

At another school, one of the PTA members also mentioned that community members observed that a previous study on rota virus caused children who participated in the research to develop complications such as stunting and death. Lack of dialogue between researchers and participating research communities during and after the study often made people interpret certain research procedures as evil or to link negative outcomes to research.

A majority of community members demonstrated an understanding that the body needed sufficient blood to function properly. Concerns were therefore expressed among FGD participants around research projects that were perceived to be taking frequent or large amounts of blood among sick people. They claimed that this contributed to blood depletion [anaemia], ill health and death of research participants. Talking about this issue, one FGD participant commented:

> *'My friend told me her experience of a child who participated in research. If they go [to the health facility] for instance today, they would take blood and if they go again next month they would also take blood until the child died. That's why she was saying research is bad, her child died because they [researchers] took so much blood every now and then'*
>
> Female FGD participant, urban setting-FGD003

This quote emphasises a point that women talked among themselves about their experiences of participating in research. In this case, her friend attributed the death of the child to anaemia because researchers drew blood each time they went for clinic visits.

In addition, some parents also felt it was inappropriate to draw blood from children because some of the children were undernourished. For instance, a certain man in the rural case study

refused to enrol his child in research involving a malaria test because he feared that the child's blood could ‘finish’. According to him, he felt that the researchers didn't have to draw blood for malaria tests when people were starving due to the famine. Similar views were also expressed by some women as to why researchers needed blood from children who were starving. This shows that a mix of both local and bio-medical knowledge that the body needed food and blood to function led to community resistance because drawing blood was considered risky to the child.

Partly, the disappointment with drawing blood as part of research procedures was due to the confusion between research procedures and clinical assessment or treatment. As previously explained, many people participated in research to access clinical assessment and treatment. This shows that such people expected researchers to diagnose the child and offer treatment. Negative outcomes such as death after research participation however affected their trust in research and led to suspicions that health researchers had 'evil' intentions. Such negative outcomes after participating in research therefore strengthened the relevance of the rumours that health research was evil because it led to death. Since information in these communities circulated by word of mouth, these stories influenced resistance particularly in urban settings. For example, a focus group participant and a mother to a research participant from urban settings commented:

'These are the fears that we have...a researcher can come to say that they will conduct research and draw blood samples. And when they draw blood...some people start to scare you even when they draw mucus only [take a nasal swab], they say ' If they draw blood or mucus, will the child get better? Eventually, some people get discouraged to participate'

Male FGD participant, urban setting-FGD 004

'... I asked myself aa! If they draw blood from my child frequently, will the child really get better? They keep coming and coming and each time they come, they draw blood...so will the child get better? That is why I made a decision to withdraw [from the research]'

Mother of a research participant, Secondary education, urban setting-SSI017

In the first quote, a man stresses that some people discouraged others from participating in research because it did not offer treatment. Similarly, in the second quote, a woman also expresses her disappointment with the extractive nature of research where they just drew blood and the child did not get better. Consequently, individual testimonies about negative experiences with research were communicated to other community members to demonstrate the evils of health research and this led to community resistance. In the next section, I will explain local beliefs in relation to blood and participation in health research.

7.3.2 Intersection between local beliefs and study procedures

One of the common beliefs in both urban and rural settings was that some people involved in *satanic* cults were killing people mysteriously in order to use the blood for rituals and acquire more wealth, and this has also been reported elsewhere (Ashforth, 2014). Due to socioeconomic inequalities between researchers and communities, most of the researchers were perceived by communities as being affluent because of the project vehicles they used and other resources. Participation in research involving blood samples was associated with satanism because some community members believed that researchers acquired wealth by 'sucking' blood and selling it for satanic rituals as shown in the following quote: *When they take blood, they sell it to other people...who will use the blood for satanic rituals and you just lose your blood* (Female FGD participant, Urban setting-FGD001). Other FGD participants also explained that participation in research involving blood samples was being seen by the community as part of the initiation into the satanic cult. Since a majority of the population in

Malawi were Christians or Muslims, initiation or association with people involved in satanic cults was considered as evil or a taboo. Such people who were associated with satanism were therefore discriminated from others out of fear that they may cause calamities such as accidents and deaths in the community. One FGD participant from an urban setting reported: *Because I participated in a research that took blood samples...they said regardless of how small the amount of blood was, they make a lot of money when they sell it in South Africa. So, they give us money [compensation] in return. They said I was satanic too* (Female FGD participant, urban setting FGD 003). This link between blood and satanism therefore led some people to associate research with evil and exploitation. As a result, death of a research participant was attributed to the link between drawing blood and satanism.

Due to absence or poor communication between researchers and community, most of the FGD participants also indicated that they were uncertain of how blood was used for research purposes. Interestingly, drawing blood for healing purposes was not a strange phenomenon particularly in rural settings because some indigenous healing practices [*mphini or kutemera*] also involved blood. It is also likely that the vernacular term for vaccine [*kutemera*] was derived from the indigenous preventive and healing practice of *kutemera*.

Some participants in the rural setting indicated that there was an indigenous practice of making small incisions on the veins of a person who was presenting with symptoms such as headache, fever and vomiting. If an individual was presenting with these symptoms, an elder or a traditional healer would cut small incisions using a razor blade to let the 'bad' blood come out. In some cases, traditional healers used to put traditional medicine on the incision and covered it up with a small cloth. In general, most community members either practiced or were aware of this indigenous healing practice involving blood. What is surprising is that, most people had fears of blood samples in health research and two reasons emerged from the analysis to explain their fears. First, FGD participants claimed that they were not aware of

how blood was used for research purposes, as such, they suspected that researchers took away blood samples to use them for evil purposes. For instance, one participant commented: *When we take the blood out, we throw it away but the researchers take it away to do bad things with it...* (Female FGD participant, rural setting-FGD010). Second, local beliefs in relation to evil things concerning blood also compounded fears with certain research procedures as it will be shown in the next paragraph.

More generally, these pre-existing local beliefs in relation to satanism, blood drawing and research participation impacted on community resistance. As previously explained, enumeration of households for research purposes and labelling them with stickers in the rural case study raised fears among community members in some villages that they were going to be initiated into the satanic cult. According to their religious and local beliefs, they believed that in the last days satanists would deceive people and mark them with the figures '666' as part of the initiation. As such, they suspected that the research may initiate them unknowingly into satanism by marking their homes with the stickers. In addition, introduction of mosquito traps which were new in this setting also raised suspicions that the research was satanic. In order to assess whether the population of mosquitoes was reducing, field workers were leaving mosquito traps in selected households to stay overnight (See figure 7.3). Most people however believed that evil things or witchcraft [*ufiti*] took place mysteriously at night to cause ill health, disabilities or death. Some people therefore expressed initial fears that the strange looking mosquito trap was going to suck their blood mysteriously while sleeping. Commenting on the issue, two FGD participants reported:

'When they were leaving the house with it, it would make a sound woo!!! So, people were confused, they were like aa! Maybe they are collecting blood...It's like when you get close to it, it would make a sound like a fan voo!'

Male FGD participant, rural setting FGD 013

'When they brought it to my house, I asked them what is the purpose of having this and they answered. And then I told them, look! It looks like something used by witch doctors, do you want to take our blood? They explained that they just wanted to find out if there were mosquitoes in the house and I was satisfied with the answers...it looked like a calabash and then it had something like a bell at the centre...it wasn't any different from what witch doctors use. It also had a gallon and they were things in it. One would wonder what was the purpose of all those'

Male FGD participant, rural setting-FGD016

This shows that the introduction of mosquito traps in this setting led to fears because of the association between research, blood drawing and evil. Since the mosquito traps resembled articles used by witch doctors to cause calamities on other people, this led community members to suspect that mosquito traps were introduced to cause calamities too.

Figure 7.3: A mosquito trap set up in one of the houses

7.3.3 Effects of perceived benefits on agency in the context of hospital-based studies

While research staff attributed research participation to effective community engagement, research participants' perceived benefits of research participation in hospital based studies impacted on their agency. This was evident particularly in the hospital case study where consultation FGDs were conducted to understand perceptions around bronchoscopy and to improve understanding of the study information among potential research participants. The researchers incorporated feedback from FGD participants and used visuals to illustrate the bronchoscopy procedure with an aim of improving informed participation in research. Despite having higher education levels, most of the research participants demonstrated challenges to differentiate between research and clinical assessment. As such, decisions to participate in research were driven by the need to access clinical assessment or treatment rather than an understanding of research objectives.

As previously discussed, health services offered in public health facilities were characterised by shortages of staff, drugs, equipment and long waiting lines, some people therefore participated in hospital based health research to receive better care and treatment. Some of the research participants shared positive experiences of spending less time at the hospital and accessing better treatment. In this case study, the research participants had TB and they needed treatment. As such, they participated in the research project to benefit from better clinical care and treatment offered by the research staff. For example, one research participant commented: *Because of this disease [TB], I knew that there was a problem in my body. After they explained to me, I was convinced and I thought it was wise for me to [enrol in research] to know what was wrong in my body* (Female research participant, secondary education -SSI026). Another research participant commented: *You know what? There are many people who are sick but they are still in the village because they do not know how the body is functioning. But when you come here and participate in a research, for me I feel it is a good thing because they provide advice for you to get better* (Male research participant, secondary education- SSI027). These two quotes therefore show that some research participants enrolled in this hospital based study to access clinical assessment and advice.

Despite widespread concerns that researchers took blood to sell to satanists, these rumours did not seem to discourage participants from participating in this hospital based research. This could be because the study was being conducted in a tertiary hospital that offered specialist care. Thus, it was more acceptable to give blood samples in hospital settings. It is also likely that participants fears may have been overpowered because of the need to access better treatment. During an interview with one research participant, he claimed that research participants used to chat among themselves when they met for clinic visits that blood infected with TB could not sell. Through this peer support as well as encouragement from other

family members, the research participants adhered to research procedures and underwent frequent blood tests with expectations of treatment as shown in the following quote:

> *'As for me, I was not very scared because I had asked my aunt and she said that it was a good organisation [research] because it follows a person until they finish treatment...if you participate in this research, you shall get better. If they want to take your blood, let them take it. You shall see the benefits later'*
>
> Research participant, hospital case study- SSI 003

Because the research participants expected healing, some individuals who participated in the research associated their healing to participation in research. For instance, one study participant who had been participating in the bronchoscopy study for more than six months indicated that he had been cured from TB because the bronchoscopy procedure cleansed his lungs. Challenges to explain or understand the bronchoscopy procedure may have led him to understand that the fluids inserted in the lungs were meant to cleanse the lungs. Having gone through bronchoscopy research procedure, the participant also claimed that he felt better and he was able to eat properly. The comment below illustrates his understanding of the research procedure and benefits to his health:

> *'I went, and they washed my lungs. That time when I go home to eat I would only finish one lump of nsima [corn meal] and then take my medication. I would really force myself to eat. After cleaning my lungs properly, my sister brought nsima. I ate two lumps of nsima and I felt the nsima wasn't enough...after the last washing [bronchoscopy] I don't feel any body pains or anything'*
>
> Male research participant, secondary education, hospital case study-SSI028

Since health services in public hospitals were considered to be of low quality and researchers offered better medical care, some research participants enrolled in hospital based research with expectations of clinical assessment, treatment and other perceived benefits. This case study shows that research participation in hospital based studies led to subjective or conflicting views about the value of a research project to participating individuals. In this case, the research participant claimed that the bronchoscopy procedure made him to feel better while the researcher claimed that bronchoscopy was a procedure that could not heal an individual.

7.3.4 Community's reliance on social capital and study acceptability

Since research or health interventions were sometimes associated with evil and viewed with distrust in both settings, decisions to participate in research were validated through personal or shared experiences of the risks and benefits within their social networks. Information gathered from these social networks therefore impacted on individual or collective decisions to participate or resist research.

Since most of the participating research communities had a history of oral tradition and relied on verbal communication, people's experiences with research were usually circulated beyond the community in social gatherings. First or second-hand testimonies or rumours obtained from family, peers or neighbours were therefore considered more reliable to some people than information from outsiders such as health care workers or health researchers. Thus, community members first-hand experiences or rumours from people within their social networks often impacted on collective or individual decisions to participate or resist research.

A notable example to illustrate community members reliance on social capital for information sometimes impacted on community resistance was shown in the urban case study. During the course of implementing the study, primary school students from one of the schools protested that they did not want the research at their school because they suspected field workers of 'blood sucking'. This incident happened following several media reports of individuals whose blood had been sucked mysteriously in some districts. This shows that the children's shared beliefs of satanism and blood sucking, and the media reports resulted in collective power to resist the research. This again shows that the children acted based on their shared belief that the research could harm them and resulted in collective agency.

In contrast, shared experiences of the interventions in the rural case study facilitated collective acceptability of the interventions. As discussed previously, research staff in the rural setting indicated that some community members were initially scared with the interventions because of the links between research and satanism. They claimed that these fears were cleared when participants saw benefits such as test results, malaria drugs and a reduction in malaria cases. For instance, after community members saw the benefits of undertaking the malaria tests, other people who were not randomly selected started demanding malaria tests to know their results and receive medication. Likewise, initial fears that mosquito traps would suck human blood were cleared when none of the community members reported negatives experiences with the mosquito traps within their social networks. Some people begun to say that the mosquito traps helped to reduce the mosquito population by 'trapping mosquitoes'. In addition, research staff and community members claimed that information about people's experiences of the interventions spread beyond intervention villages. As a result, some people in non-intervention villages also started covering their windows with bed nets because they heard positive experiences that covering windows prevented mosquitoes from entering homes. This shows that collective experiences of

research benefits had implications on reproduction of study information and adoption of interventions beyond intervention villages.

It is also worth noting that, in these settings folktales or folklores based on past events were traditionally used to communicate certain messages or teach moral values. Similarly, decision making around participation or resistance of health interventions was not always based on 'evidence based information' presented by research staff but previous experiences, stories, rumours or folktales within their social networks. This shows that decision making around research participation did not necessarily depend on an understanding of bio-medical information alone because decisions concerning research participation were often validated based on experiences or influence of other people within their social networks.

7.4 Conclusion

Although community engagement was used to improve informed participation and study acceptability, decision making was dependent on effective communication, historical or lived experiences with research, hybrid knowledge generated from scientific and local knowledge, perceived benefits of research, lay interpretations of certain research procedures as well as community's reliance on social networks for information. These findings therefore challenge assumptions that associate literacy alone with positive outcomes or rationality (Wickens and Sandlin, 2007) without taking into consideration broader contextual factors.

While the intention of research staff was to communicate scientific knowledge or health research and encourage participation, successful communication of scientific knowledge depended on proper alignment of the communication approach with pre-existing communication and knowledge. As research staff and community members interacted and exchanged information, community members developed their own meanings of the research projects which later became widespread as reality. This new 'hybrid' knowledge or 'reality'

therefore facilitated research participation or resistance. Knowledge re-production among community members was therefore a continuum that depended on social interactions between multiple research stakeholders, socio cultural factors as well as mutual influence of scientific knowledge on local knowledge.

These results suggest that integrating scientific knowledge and local knowledge remains a challenge. The experiences and examples from research participants in this chapter demonstrated some of the factors that potentially affected research participants agency. These findings also raise questions on how research participants in these settings can exercise their agency and make autonomous decisions to participate in research in the context of 'hybrid' knowledge. Drawing on findings presented from chapters five to seven, the following concluding chapter will discuss the complex interplay between issues of knowledge reproduction, ethical research and study acceptability.

Chapter 8: Discussion and conclusion

8.1 Introduction

This thesis aimed to explore social interactions among research stakeholders and consequent effects on community engagement, ethical research, knowledge re-production and study acceptability. As outlined in the literature review, few empirical studies have focused on understanding factors shaping community engagement processes, ethical research and study acceptability in neo-colonial settings. This study was therefore undertaken to contribute to this knowledge gap by using three ethnographic case studies from an urban and a rural setting in Malawi. A qualitative study design was used to examine processes and outcomes of engaging with communities. Data collection approaches included: participatory workshops, participant observation, interviews and focus group discussions with various research stakeholders. I presented the results from the case studies under three main themes: factors shaping community engagement; ethical issues situated between community engagement, study design and implementation; and finally, knowledge re-production and study acceptability in the context of community engagement. The next section will discuss emerging issues from these results in light of theoretical and empirical work on community engagement.

8.3 Discrepancies between moral intentions and pragmatic application of community engagement

Community engagement strategies employed in the three ethnographic case studies reflected 'deficit models' of engagement because communities were engaged to be informed about the research projects. According to Bauer (2007), models of improving public understanding of science were criticized in the early 2000 because of their assumption that the public is ignorant. In place of these, participatory public engagement was recommended to build

public trust in scientific projects. In addition, participatory processes of engaging communities in the conduct of global health research were also recommended in the CIOMs guidelines as a means of showing respect to communities and building equitable collaborative partnerships between researchers and community stakeholders (Council for International Organisations of Medical Sciences., 2016). In practice however, there are no national or institutional regulatory requirements to comply with ethical guidelines on community engagement. These results support observations from previous studies that community engagement is perceived in narrower and instrumental terms as a means of clearing community concerns, satisfying funder requirements, increasing visibility, and maximising study participation and acceptability (Angwenyi et al., 2014, Participants in the Community Engagement and Consent Workshop, 2013, Marsh et al., 2008a, Kamuya et al., 2013, Nakibinge et al., 2009, Nyika et al., 2010). This shows a discrepancy between the ideals in the literature on participatory community engagement processes and the reality on the ground. A number of reasons could explain this discrepancy both at the macro and micro levels such as: community's lack of awareness of the democratic ideals around community engagement (8.3.1); imposition of community engagement frameworks (8.3.2); lack of successful examples of collaborative partnerships (8.3.3); challenges to balance between incorporating community feedback and complying with conventional scientific guidelines (8.3.4) and historical experiences of colonialism (8.3.5). The section below describes these factors in detail, but these have not been ranked in terms of importance.

8.3.1 Low awareness of the democratic ideals around community engagement among research stakeholders

A majority of research stakeholders were not aware of the existence of ethical guidelines on community engagement. As previously communicated, there were also no regulatory requirements at the national level to comply with ethical guidelines on community

engagement and collaborative partnerships. As such, researchers used community engagement to improve research participation, thereby perpetuating assumptions of increasing scientific literacy with an aim of improving recruitment. Even though community engagement was used as a means of informing communities to empower them to make informed choices, community stakeholders were not empowered with information about collaborative partnerships or research ethics. Results from this study also show that the community engagement approaches involved an exercise of biopolitics by employing community engagement to manage populations to adopt behaviours defined by bio-medical researchers. For instance, community engagement was used in the rural case study to facilitate community participation in interventions defined by bio-medical researchers such as larval source management, bed net use and house improvement. Drawing on Gaventa's analysis of power, one can argue that participating research communities were not given the space to participate in decisions concerning which interventions to implement (Gaventa, 2006). On the other hand, tailoring the interventions to suit diverse community needs could have affected implementation of the cluster randomised trial as reported by Cyril (2015). More generally, these findings show that the ideals of collaborative partnerships may not work in settings where participating research communities are not aware of these guidelines or where researchers need to comply to international scientific requirements as shown in section 8.3.4. This also leads me to question the relevance of imposing international guidelines to determine how to engage with communities rather than allowing community members including research participants to determine their rules of engagement. While I acknowledge that a lack of regulatory requirements to comply to participatory community engagement processes facilitated deficit models of engagement, it is necessary to understand the relevance of applying international frameworks on community engagement to promote

collaborative partnerships. In the next section, I will discuss the relevance of applying these international frameworks to rebuild trust in neo-colonial settings.

8.3.2 Imposition of community engagement frameworks from western settings to rebuild trust in neo-colonial settings

Since I have shown in chapter two that the rationale for public/community engagement was slightly different across western and African settings, the question still remains if international frameworks on community engagement should be used to rebuild trust across different settings. In reviewing the literature, I found that failed scientific projects and surveys conducted in western settings led to recommendations that promoted active engagement of the public in scientific projects in order to rebuild trust (Bauer et al., 2007). In addition, community activism to be involved in decision making concerning research also led to increased support for community engagement in western settings (Slevin et al., No date). Following this, community engagement became a requirement by US and European donors in global health research despite the differences in terms of education and research literacy between communities in western settings and in developing settings (Slevin et al., No date). Given that the need to engage communities in western settings was 'public/activists driven' to promote coproduction of knowledge while in Africa community engagement was 'researcher driven' to strengthen relationships, extrapolating these context based recommendations from western settings to other settings remains questionable. Thus, extrapolating these recommendations in other settings follow neo-colonial assumptions of determining terms of engagement between powerful countries and neo-colonial states to yield ideals of powerful outsiders of community empowerment. In addition, considering that community engagement aims to promote community empowerment (Whittaker and Smith, 2015, NICE., No date), it is paradoxical to impose universal guidelines or frameworks to guide engagement processes. Challenges to implement 'researcher driven' community

engagement approaches to strengthen collaborative partnerships have also been widely reported in non-western settings as it will be shown in the following section.

8.3.3 Few successful examples of collaborative partnerships in the context of health research in low resource settings

Lack of successful examples on how collaborative partnerships might work in the context of unequal power structures in low literacy settings (O'Mara-Eves et al., 2015, Musesengwa and Chimbari, 2015) may have reinforced the relevance of deficit models of engagement. Since a majority of publications on community engagement in low literacy settings have reported benefits of using information sharing or community consultation activities to improve informed participation or recruitment (Nyika et al., 2010, Tindana., 2011, Tindana et al., 2015), researchers in similar settings employed related activities for instrumental reasons to facilitate study implementation.

In addition, challenges to engage communities through the use of collaborative approaches such as CAGs, CABs, research volunteers or community representatives have been widely reported (Kamuya et al., 2013, Lwin et al., 2014, Shubis et al., 2009). CAGs and other community representatives are engaged in research to provide a mechanism for community consultation on research design in order to minimise potential risks of research to participating communities (Strauss et al., 2001, Quinn, 2004). A number of studies in resource poor settings have however shown that these community representatives fail to perform their expected roles in research but see their involvement in research as an opportunity for financial gain or self-development (Lwin et al., 2014, Pratt et al., 2015, Morin et al., 2008, Chantler et al., 2013, Kamuya et al., 2013). More generally, challenges to engage community representatives as collaborators have been attributed to power dynamics between researchers and CAG members due to low science and ethics literacy, and limited access to

resources independent from the research projects that they advise on (Pratt et al., 2015, Brieland, 1971). This shows that pre-existing power imbalances between researchers and community due to scientific literacy and access to resources influence community engagement practices.

Similarly, studies involving PPI in the global north have also reported challenges such as: difficulties to comply to scientific procedures, lay representatives feel inferior to make contributions, lay perspectives are sometimes dismissed by researchers and that PPI is costly and time consuming (Dudley et al., 2015, Brett et al., 2014, Johnson et al., 2016). Collectively, findings from studies conducted in the global north and the global south have shown few successful examples where lay perspectives have influenced the conduct of research or where communities are engaged as collaborative partners. A possible explanation for this is that, biomedicine involves biopower which may limit equitable participatory interactions between bio-medical researchers and community partners as it will be shown in section 8.3.4.

8.3.4 Challenges to balance between incorporating community feedback and complying with conventional scientific guidelines

While I agree that communities should be engaged in participatory processes in the design and implementation of research, practical application of the democratic ideals in the conduct of bio-medical research raise a number of questions. Firstly, bio-medical research involves compliance with conventional scientific procedures as well as international ethical guidelines. For instance, ethical guidelines state that research personnel must have relevant training as well as ethics education (Council for International Organisations of Medical Sciences., 2016). This shows that the conduct of bio-medical research employs mechanisms of control and coercion to ensure that researchers comply to conventional guidelines. While community

stakeholders may have political space to make suggestions on the conduct of bio-medical research at a local level, there may be challenges for community stakeholders to claim spaces for participation and influence change at the global level. Such hierarchical power structures therefore limit the extent of community participation in the conduct of bio-medical research.

In addition, while professional certification may authorise an individual to represent scientific interests, the technical expertise required in bio-medical research makes it difficult for community partners who do not have this expertise to contribute effectively in decision making. For instance, previous studies evaluating patients or community involvement in research design indicated challenges around balancing between incorporating patients or community's views in research and complying with acceptable research procedures (Gillard et al., 1999, Cyril et al., 2015). In addition, power dynamics between researchers and communities due to technical expertise required in the development of research restrict patients from contributing or negotiating decisions with researchers (Brett et al., 2014, Johnson et al., 2016). These findings support the observation that bio-medicine is generally perceived as superior to improve health compared to other models of health (Lupton, 1997). In addition, bio-medicine often employs biopower to manage populations and individuals to adopt behaviours that may interfere with individual choice (Gastaldo, 1997). Consequently, the biopower in medicine that allows bio-medical professionals to prescribe how others should behave renders community stakeholders in a powerless position to challenge or negotiate decisions. In other words, interactions between bio-medical researchers and community stakeholders are shaped by invisible and hidden power relations that determine ideological boundaries of participation and which views to incorporate or dismiss. While I appreciate that researchers are trained and paid to conduct quality research and are accountable to funders, researchers' obligation to conform to scientific procedures and

international research ethics may render community engagement tokenistic if community feedback deviates from internationally acceptable research procedures. Given the challenges presented in several studies around engaging patients or communities in research, the question still remains if trying to share equal decision-making power is feasible. In addition, historical experiences of colonialism and authoritarian power structures may also render the democratic ideals of collaborative partnerships difficult to implement as it will be shown in section 8.3.5.

8.3.5 Historical experiences of colonialism and autocratic power structures

The results of this study showed that historical experiences of colonialism, autocratic power structures and consequent unequal power relations and social norms of engaging with service providers may have exacerbated implementation of deficit models of engagement. In chapter five, I reported that community members did not expect to engage in collaborative partnerships with researchers. This finding however has to be interpreted with caution given the post-colonial history, political context in Malawi as well as experiences of engaging with other service providers.

As previously reported in chapter two, the introduction of bio-medical research coincided with colonial conquest. In order to encourage compliance to public health interventions, the colonial administration prohibited indigenous healing practices and issued fines or physical beatings for non-compliance (Graboyes, 2010, Hokkanen, 2015). Colonial public health was therefore a dimension of colonial hegemony and social control where science served to legitimize cultural superiority' (Geissler, 2011). The contribution of this study has been to confirm that historical experiences of colonialism continue to shape power relations between bio-medical professionals and local communities in the context of community engagement.

Bermúdez (2016) argues that *'people with a history of being colonized continue to suffer the effects of colonization through practices that keep them in oppressed positions'*. Similarly, Freire (1972) also argues that the perception of people in oppressed positions is impaired by their immersion in the reality of oppression such that they perceive themselves as members of an oppressed class. In the first place, the researchers aim of conducting research inadvertently reinforces views that problematize the community while portraying bio-medical ideas as legitimate to improve people's welfare. Thus, the bio-medical ideas are privileged, and *'subordinates internalise this inferiority by believing that the dominants group's ideas are more legitimate and idealised'* (Bermúdez et al., 2016). As a result, lay community members may feel incompetent to challenge bio-medical ideas because they are considered more legitimate to address health challenges or they may perceive their local knowledge as insignificant. Drawing on Foucault's views of the links between power, knowledge and discourse, Hall (1992) also analysed how colonial discourses about developing countries influence knowledge and social practices. He therefore argued that the colonial discourse developed in the global north in relation to other countries has important implications on how they behave towards others (Hall and Gieben, 1992). As such, social interactions between Europeans and others cannot represent an encounter between equals because Europeans positioned themselves in dominant power 'for having discovered people who had no wish of being discovered' (Hall and Gieben, 1992).

In addition, Magolowindo (2007) has argued that 73 years of colonial rule and 30 years of dictatorship in Malawi created a culture that does not promote democratic values to encourage public participation and tolerate divergent views. As previously indicated in chapter three, Malawi was under an autocratic government after gaining its independence in 1964. During the 31 years of autocratic leadership, anyone who criticized the government or the leadership was tortured or murdered and this led to a 'culture of silence' and fear among

the people to express their views to those in authority (Manda, 2002). Despite introducing democratic reforms in 1994 to strengthen citizen participation in decision making, challenges have been reported to integrate democratic principles alongside autocratic leadership structures (Chiweza, 2007). As such, the state of democracy in Malawi has been described by Englund (2007) as a *'culture of chameleon politics'* that does not promote western democratic values.

Challenges to integrate democratic or participatory values have also been reported in health service delivery in Malawi. For instance, the Ministry of Health outlined provisions to enhance community participation in health service delivery through village health committees and health facility advisory committees. Even though these committees are tasked with the responsibilities of monitoring drug usage, identifying health needs and facilitating dialogue between health care workers and community, it has been reported elsewhere that most of these committees are non-functional (World Health Organisation., 2014). This could either be due to the 'culture of silence' or because community members are not empowered to demand accountability from leaders (Chiweza, 2007). Since principles of collaborative partnerships require participatory processes, the success of engaging community partners in decision making would depend on empowerment of community members to voice their needs as well as abilities to negotiate decisions with the researchers. Given the challenges experienced in the implementation of participatory governance programs in Malawi (Chiweza, 2007), It is therefore likely that community partners would consider decisions made by bio-medical researchers as final because of their expertise in bio-medicine, thereby facilitating non-participatory engagement. In other words, democratic participation in the conduct of global bio-medical research may not work effectively in neo-colonial settings such as Malawi due to community members inability to express their views to powerful outsiders.

In the same vein, Swidler (2007) wrote about paradoxical effects in relation to efforts by foreign donors to mobilize and empower communities to solve their own AIDS related challenges. Using surveys, interviews and ethnographic data from rural Malawi, Swidler (2007) argued that '*processes of community mobilization and empowerment were far from what was envisioned by donors'*. Even though the basic assumption of community participation is that '*communities have better understanding of what they need'*, processes of engaging communities were described as instrumental rather than democratic because communities were limited to ask for resources that donors deemed sustainable and they were not empowered to voice their needs. In addition, development projects that aimed to empower communities failed to address underlying power inequalities between NGO staff, volunteers and communities but rather 'sustained the fortunes' of NGO staff. In so doing, volunteers and communities used their ingenuity to satisfy donors expectations while pursuing their own agendas to fulfil their needs for jobs and incomes. Due to this disconnect between community needs and donor priorities, Swidler (2007) points out that NGO projects failed to yield to donors' beliefs about empowerment and sustainability. Similarly, this thesis provides an insight that the community engagement approaches in this neo-colonial setting were tokenistic due to underlying power inequalities and challenges to negotiate conflicting interests of research stakeholders. I however acknowledge that lay community members in other contexts that do not have a colonial history may equally feel incapable to engage in equitable collaborative partnerships due to the technical expertise required in research design as shown in section 8.3.4.

Considering all of this evidence, it seems that colonial patterns of behaviour are replicated in the context of community engagement. Participatory processes of engaging communities were introduced to ensure that local voices that have been previously ignored or disregarded should be incorporated in the design and implementation of research or development projects.

On the other hand, bio-medical research is seen to privilege voices of powerful actors such as academics, scientists and other local elites to determine the topics of research and methodology. Instead of involving people who have been historically excluded from the production of knowledge, findings from this study and others show that views of local people are rarely incorporated in the conduct of global health research. What follows is an account of outcomes of community engagement on ethical research in this neo-colonial setting.

8.4 Outcomes of community engagement

8.4.1 Undesirable consequences of engaging community leaders

Even though some studies have shown that securing buy in from community leaders is essential for successful trial implementation (Nyika et al., 2010, Tindana., 2011, Musesengwa and Chimbari, 2015, Angwenyi et al., 2014), findings from this study support previous contradictory research that this can compromise individual's autonomy to consent to participate (Angwenyi et al., 2014, Graboyes, 2010). While it is socially acceptable for community leaders to exercise their coercive power in order to ensure that communities comply with public health interventions, it is worth noting that community members agreement to volunteer in research may be influenced by threats from community leaders. This finding is similar to Angwenyi (2014) who reported that '*some chiefs exerted pressure on people to enrol in research by threatening to withdraw people from a local food for work development project and that they would arrest rumour mongers'*. Similarly, Okello (2013) reported challenges in obtaining assent and informed consent in a school based cluster randomised trial in Kenya. These challenges were attributed to misperceptions about the study procedures, exclusion of children in community engagement activities as well as hidden social pressure among children to conform and avoid reprisal from parents.

Collectively, these studies show that community engagement alone was not the only solution to improve informed participation nor was a signed consent form an indication of informed participation. Rather, engaging community leaders particularly in rural settings exerted pressure on individuals to consent or withdraw from research and thereby compromised an individual's autonomy.

On the other hand, I acknowledge that other studies have shown that community engagement improved informed participation in research. In cases where community engagement was reported to improve informed consent, Boga (2011) for instance, reported that they engaged with communities to develop context relevant consent forms for different study designs at KEMRI. As such, this exercise helped to improve community understanding of study information before giving consent. Nevertheless, community engagement has been instrumental in most African settings to strengthen relationships between researchers and communities by responding to local community needs for development and monetary allowances, study acceptability and participation in research (Nakibinge et al., 2009, Nyika et al., 2010, Vallely et al., 2007).

Surprisingly, while there was evidence to suggest that some community leaders influenced people to participate in research in rural settings, there was no evidence of this in the urban setting. Three possible explanations might be due to the differences in the leadership structures, economic factors and study designs. Firstly, village leaders in urban settings were not as powerful probably due to urbanisation and rapid population growth. Most people who migrated to urban settings either owned the houses or lived in rented houses, and they were relatively economically advantaged. As such, the community leaders could not threaten people that they will be chased away from the houses that they owned or rented. In addition, the study design in the urban setting required individual participation. Thus, village leaders could not easily know participants who were randomly selected or influence their decisions.

On the other hand, the village leaders in the rural setting may have been influential because most community members were economically disadvantaged and relied on them to select beneficiaries for various development projects as well as to settle disputes. Since the study required collective participation, village leaders could easily use their coercive power to impose fines and ensure that their villages excelled in the implementation of the interventions. Another study also reported that some families in Malawi complied to maternal health interventions to deliver in health facilities out of respect for community leaders or fear of fines (Walsh et al., 2018).As such, a range of these multifaceted factors in a given context impacted on an individual's decision to participate in research.

8.4.2 Discrepancies between researchers and community members' perceptions of study benefits, compensation and undue influence

While community engagement is promoted to enhance mutual benefit sharing between researchers and communities, one of the issues that emerged from the findings was that global health research has reinforced colonial patterns of domination to influence what is deemed as fair benefit or exploitation. Ethical guidelines for health research state that '*from the inception of research planning, it is important to ensure full participation of communities in discussions of the relevance of the research for the community, its risks and potential individual benefits, and how any successful products and possible financial gains will be distributed.*' (Council for International Organisations of Medical Sciences., 2016). I however indicated in chapter six that there was a discrepancy between communities' views of study benefits and what researchers viewed as appropriate compensation, fair benefits or exploitation. This shows that community engagement approaches did not effectively involve communities in discussions concerning the research benefits. As such, a majority of people participated in research in order to access individual benefits such as treatment as well as financial incentives rather than to promote public health benefits, and these results are in

agreement with previous studies in low resource settings (Angwenyi et al., 2014, Graboyes, 2010, Fairhead et al., 2006). This discrepancy in terms of how research benefits are perceived therefore leads me to argue that the agenda for promoting research benefits naively follows neo-colonial patterns by privileging views of powerful outsiders including local elites on what should be considered as fair benefits. Partly, this could be due to the presumption of a '*local community as having consensual needs and interests'* (Swidler and Watkins, 2009) as shown in section 8.4.3 below.

8.4.3 Questions around what constitutes the 'host community' to benefit from research

While it is widely agreed that research must benefit host communities, there is a lack of consensus on what constitutes the host community that should stand to benefit from the research (Hughes, 2014). The empirical findings from this study raise intriguing questions around community views of micro and macro level benefits. Firstly, findings from this study demonstrated that community members viewed micro level benefits such as financial compensation and treatment as justifiable benefits rather than the macro level benefits. This has also been reported by other authors from Kenya that study participants appreciated direct benefits such as health care and compensation for their participation in research (Kamuya et al., 2014, Lairumbi et al., 2012). Secondly, while the researchers considered hiring and training of local staff for field work positions as contribution to strengthen research capacity, community members did not perceive this as a justifiable benefit. This was because the understanding of 'local staff' varied between community members and researchers. For instance, a majority of community members in the rural case study expressed dissatisfaction with health researchers and other service providers for hiring staff from other districts. They preferred that staff should be hired from their villages but it was challenging for the researchers to hire staff from the villages due to low literacy levels. Nevertheless, this finding has important implications for determining whether people in low literacy geographical

communities should participate in research for the benefit of other communities with higher literacy within the same country. In the next section, I will discuss how community's unmet expectations from research affect knowledge re-production, study acceptability and resistance.

8.5 Implications of community's reliance on social networks on study acceptability and resistance

More generally, participants views around participation, research benefits and risks in low resource settings have got to be understood in relation to the socio-economic and cultural context. Since the research projects were conducted among resource poor communities, it is worth noting that a majority of people in these settings rely on social networks for social security. For instance, community members relied on mutual support from neighbours and family during social events such as initiation ceremonies, weddings, funerals or even illnesses and this has also been reported elsewhere (Anders, 2002). This reliance on social networks can be well understood using theories of social capital which state that '*social networks, norms of reciprocity and trustworthiness that arise from them enable participants to act together more effectively to pursue shared objectives'* (Field, 2003). Responses from some research participants indicated that they participated in research in order to establish a social connection with research staff or support the successful conduct of the study but with an expectation of mutual assistance such as health care, employment and other financial or material benefits. This has also been reported by other authors across different African settings that conduct of health research in resource poor settings led to expectations of social relationships where researchers were expected to reciprocate participation in research by offering health care, employment and other financial or material benefits (Geissler et al., 2008, Kamuya et al., 2013, Chantler et al., 2013, Nyika et al., 2010, Angwenyi et al., 2014, Fairhead et al., 2006). This give and take relationship has also been acknowledged as

essential to support successful trial implementation in African settings (Geissler et al., 2008, Tindana., 2011, Nakibinge et al., 2009) rather than promoting equitable decision making in research.

On the other hand, communities' reliance on social networks also influenced resistance because some community members relied on advice from others to make decisions around participation. This has also been noted in other communitarian settings that an individual's decision to participate in research was heavily influenced by family, peers or social networks (Marsh et al., 2011, Nyika et al., 2010). As indicated in chapters five and seven, negative experiences of some community members shaped the community response to the research projects as the stories circulated among social circles. Consequently, such personal stories influenced community resistance to research because information obtained from social networks was considered more trustworthy. For instance, response to the urban case study was problematic in one of the school communities' due to a story that was circulating in the community around the death of a research participant. This shows that rather than community engagement, personal stories around research benefits and risks heavily influenced the community's shared views of research and decisions to participate. Concerns about blood stealing, trade in body parts and the deliberate spreading of diseases have been widely reported in Africa and these were attributed to memories of colonial war and violent exploitation (Geissler and Pool, 2006). One of the issues that emerged from these findings is that ineffective community engagement processes led to resistance due to negative experiences of the interventions. Consequently, factors that facilitated community participation in the urban setting were contingent on previous experiences with health interventions and perceived benefits rather than information alone or influence from community leaders. As such, contextual factors may affect the generalizability of data as it will be shown in section 8.6 below.

8.6 Contextual 'bias' around generalisability of data generated in village based cluster randomised trials

While principles of research ethics allow for voluntary participation in research, community members participation in research is desirable in order to reach optimum sample sizes, demonstrate the statistical power of the study and to make the results generalizable. On the other hand, community members refusal to participate in research or health interventions could potentially affect the statistical power of the study to prove the effectiveness of the interventions, thereby denying a majority of people proven interventions to eradicate health problems.

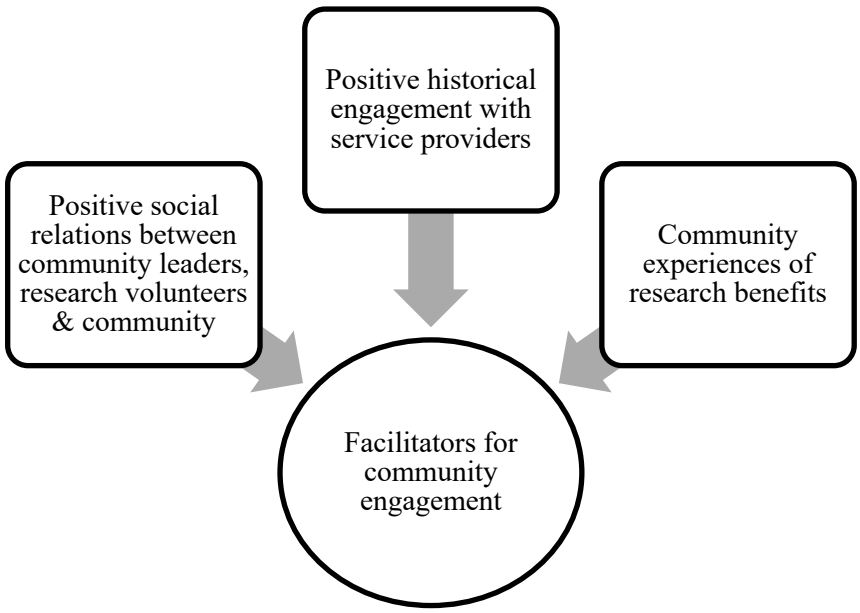
While the need to attain optimum sample sizes or high coverage rates is desirable, this need was sometimes in conflict with research ethics principles of respecting individual autonomy. On the other hand, same factors that make people 'vulnerable' and entitled to protection such as illiteracy, poverty and diseases also facilitated high recruitment rates. This complex interplay between the socioeconomic context, social norms, political context and scientific research procedures therefore raise ethical questions around conduct of research.

The rural case study demonstrated that research can either generate data to show the effectiveness or ineffectiveness of an intervention due to contextual factors presented in figure 8.1. Some of the enabling factors that promoted community participation or adoption of interventions in some villages were due to local power and social relations between stakeholders, absence of negative historical experiences with service providers and personal experiences of the benefits of the intervention. Responses to the interventions differed across the four villages mainly due to these factors. For instance, community participation was better in focal area X due to pre-existing community mobilisation structures, influence of community leaders, positive social relations among stakeholders and personal experiences of research benefits. On the other hand, previous mistrust with research collaborators and poor

social relations among stakeholders in focal area Y influenced community resistance in the interventions. This shows that the research could generate evidence to show the effectiveness of the interventions mainly due to contextual factors that promoted participation in villages in focal area X compared to focal area Y. This variability in terms of community response to interventions therefore raises ethical questions around the scientific value of research to generate data for decision making around health policies beyond the study population.

In addition, a majority of communities in the rural setting were closely knit and used to collective participation in development initiatives and this may have supported community participation in interventions such as village workshops and LSM. Such interventions that require community participation may however present challenges in urban settings due to unavailability of people at community meetings or because communities are loosely knit. Based on the empirical findings from this research, I provide study recommendations in the next section.

Figure 8.1: Contextual factors shaping study acceptability



8.7 Study recommendations

Community engagement is clearly important to empower communities to address their health needs and to improve ethical research practice. However, I highlighted several questions in this thesis that need to be considered in order to improve genuine engagement of communities and promote mutual benefit sharing in low resource settings. The following recommendations are therefore based on my theoretical understanding of community engagement, empirical findings from this thesis and experiences of community engagement processes in Malawi.

Need for mutual understanding of community engagement and research ethics among research stakeholders

Since I have shown that the ideals around community engagement were informed by failed scientific projects in western settings, I recommend that community engagement practices should be developed in response to community needs in resource poor contexts. As such, a series of participatory workshops should be conducted with community engagement experts and research stakeholders including community members from a given context to discuss ways of promoting effective community engagement in different research designs. Bearing in mind that a majority of existing frameworks for engagement do not reflect community needs for engagement in low resource contexts, outputs from the workshops should include a hand book reflecting community's needs for engagement. Rather than imposing community engagement guidelines, participating research communities should have a say in determining the rules of engagement. Most importantly, all research stakeholders must have mutual understanding of what community engagement entails.

In addition, I recommend that research staff must have relevant expertise to facilitate community engagement processes and that relevant expertise should be solicited from

community members to enable them to contribute effectively in research. In order to avoid situations where 'unskilled people are put in positions to control processes they understand little' (Ives et al., 2013), participatory workshops should be conducted to reach consensus on the types of input that should be solicited from community. For instance, lay communities could be more involved in determining research priorities to enhance the relevance of research outcomes to their setting. Instead of introducing interventions such as iron mesh or BTI that most community members may not afford, community engagement may be used to identify and test indigenous ways of preventing diseases such as malaria. Similar workshops should also be conducted to develop frameworks for educating research stakeholders in resource poor settings and to evaluate community engagement processes. Finally, efforts should be put in place to increase public understanding of bio-medical research and research ethics to effectively democratize bio-medical research and enable lay community members to coproduce bio-medical research (Pickersgill, 2010).

Multi country research on current models of community engagement

Since I have shown that there are few successful examples on collaborative partnerships in low literacy settings, some questions still remain unanswered on factors that may promote equitable collaborative partnerships in low literacy or authoritarian settings. In order to generate evidence, further rigorous research should be undertaken to provide further guidance on how equitable collaborative partnerships may be attained in these settings. This can be achieved by using multi sited ethnographic research on community engagement in multi sited research projects across different countries. Using a theory of change approach (Stein D, 2012), goals of the community engagement approaches as well as indicators for measuring success should be jointly developed with all relevant research stakeholders. A mixed methods

evaluation to assess the community engagement approaches across the different sites may help to generate evidence on the effectiveness of the approaches while taking into consideration the diverse contextual factors.

Formative work to understand the community and promote relevant research agendas and mutual benefit sharing

Given that there was a discrepancy between researchers and community members views around research priorities and benefit sharing, further research should be undertaken to identify fair benefits for participating research communities. As indicated in chapter three, a national health research agenda for Malawi was developed to highlight research priorities for Malawi. I however demonstrated in this thesis that these national priorities were not in line with participating research community members priorities. As such, further research needs to be undertaken to explore and prioritize community health needs and ensure that these needs are reflected in the national health research agenda.

In addition, further qualitative work should be undertaken to explore community's views of appropriate compensation and benefits across different study designs in order to provide a framework to research ethics committees and researchers on how to determine fair benefits to communities. One of the arguments in support of promoting community benefits states that all research relies on public goods such as transportation system and other infrastructures, as such researchers must make a fair contribution to the community (Hughes, 2014). Since, I have shown that an outsider's understanding of host community may be different from local community member's understanding of community, I recommend that community representatives have to be consulted to identify fair benefits and compensation to individuals and the community. Care however needs to be taken to balance between offering community benefits and using these benefits to influence community members to participate in research.

Finally, in order to promote genuine community engagement and accountability in global health research, certain conditions must be put in place to encourage bio-medical researchers to comply. For instance, community engagement should be taken into account when training, mentoring and appraising researchers as suggested by other authors (Federica, 2018).

8.8 Generalizability of my study findings

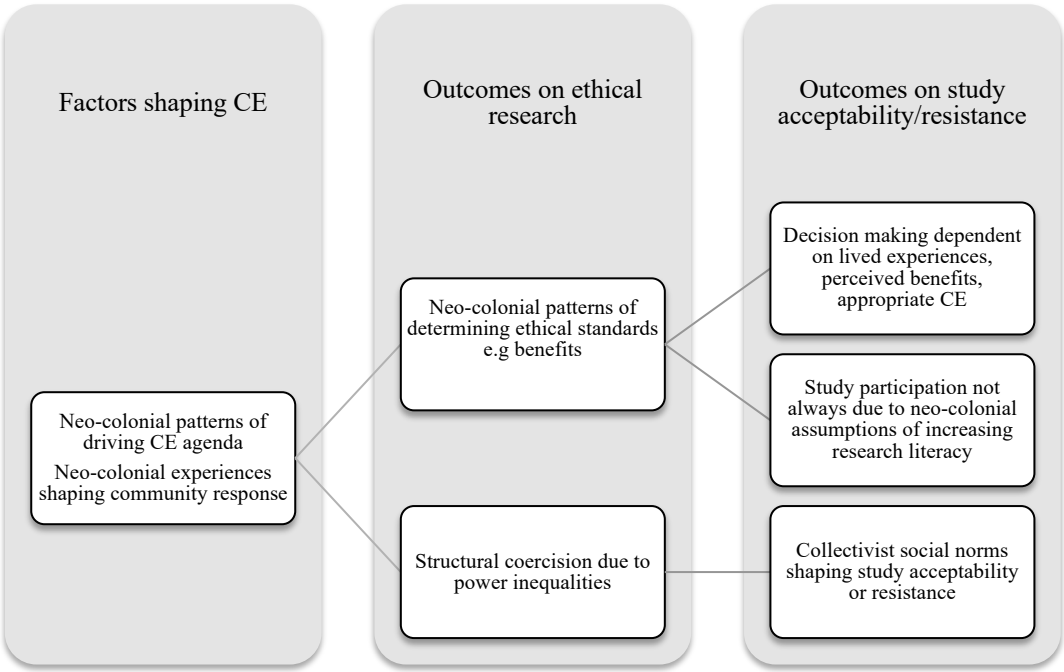
Jane Lewis and Jane Ritchie (2003) state that there are three approaches to generalisation in qualitative research. These include: theoretical generalisation, inferential generalisation and representational generalisation (Ritchie and Lewis, 2003). Theoretical generalisation concerns drawing theoretical statements from the findings for a more general application. Inferential generalisation concerns whether study findings can be generalised or inferred to other contexts. While representational generalisation concerns whether research findings can be generalised to the entire study population. The empirical findings from this study can be inferentially generalised to other similar contexts. Since I used ethnographic case studies to illustrate how community responses varied to similar community engagement activities, the results may be generalised for other settings with similar historical and socio-economic factors.

8.9 Revisiting the conceptual framework

My main interest in conducting this research was to understand community engagement and knowledge coproduction in the context of medical research. In chapter two, I presented the conceptual framework that I used to develop the research. I indicated that I was interested in understanding roles of various research stakeholders in community engagement; how power dynamics influence community engagement practices and knowledge coproduction; how risks and benefits of research are negotiated and finally, explore the risks and benefits of community engagement.

During data collection and analysis, I realised that 'collaborative partnerships or knowledge coproduction' were ideals that did not exist in practice. I therefore used theories of neo-colonialism to explain the absence of 'collaborative partnerships or knowledge coproduction' in the conduct of bio-medical research. In figure 8.2, I present a revised conceptual framework with details of how neo-colonialism influenced power relations between researchers and communities, ethical research practice, knowledge re-production (as opposed to coproduction) and study acceptability.

Figure 8.2 Revised conceptual framework



8.10 Conclusion

In conclusion, this study extends our knowledge of factors influencing social interactions among research stakeholders, contextual factors shaping these interactions and outcomes of these on the desired goals of improving ethical research practice and study acceptability. A majority of studies on community engagement have focused on sharing experiences and

evaluation of community engagement activities in a single research project within the same geographical location. Few studies have focused on understanding community engagement practices in light of theories of neo-colonial relations in research. The findings from this study offer new insights on community engagement practices in light of theories of neo-colonial relations in global health research by using three ethnographic case studies across different geographical sites.

The present study was designed to investigate the purpose, relevance and benefits of community engagement as designed by academic researchers in three health research projects. A qualitative study design was employed, using multiple data collection techniques such as participatory workshops, participant observation, interviews and focus group discussions. In addition, I also used theories of neo-colonialism to show how powerful outsiders follow patterns of driving the research agenda, determining the terms of engagement and ethical issues around benefits and coercion.

The study has shown that even though ethical guidelines promoted collaborative partnerships, neither researchers nor community members wished to engage in truly collaborative partnerships. This suggests that the ideals of collaborative partnerships as well as the researchers aims of engagement followed neo-colonial practices of imposing terms of engagement on participating research communities. The ‘silent rules’ of engagement were determined by historical experiences, power inequalities between multiple research stakeholders, social norms as well as evolving social relations among research stakeholders. These findings suggest that communities had a more instrumental role on how to engage with researchers. As such, ideals in the literature on collaborative partnerships may not be responsive to community's needs due to historical, social and political differences. In addition, lack of community activism for these collaborative ideals also raise concerns on

how these ethical standards can be successfully implemented if community members are not aware of them or if they do not demand them.

Despite ethical guidance on community engagement to improve the relevance of research to host communities, I have shown that views of researchers and community members differed on community needs, research priorities and benefits. Community needs also varied within as well as across groups raising questions on researchers' ethical obligations to respond to these diverse needs. Since the research priorities were not considered as relevant by community members, views of research benefits and exploitation also differed between researchers and community members. A majority of research participants enrolled in research in order to access individual benefits rather than collective benefits. Apart from community engagement, the broader socio-economic context, social norms and local power structures were seen to present structural coercion. As such, the community engagement approaches did not adequately protect communities from being unduly influenced to participate in research nor promoted fair benefit sharing. Rather, community engagement practices reflected neo-colonial patterns by legitimizing the research and facilitating community adoption of concerns as determined by powerful outsiders.

Finally, even though community engagement was used to improve informed participation and study acceptability, decision making was dependent on effective communication, historical or lived experiences with research, hybrid knowledge generated from scientific and local knowledge, perceived benefits of research, lay interpretations of certain research procedures as well as community's reliance on social networks for information. These findings therefore challenge assumptions that associate literacy alone with positive outcomes or 'rationality' without taking into consideration broader contextual factors. While the intention of research staff was to communicate scientific knowledge or health research and encourage participation, successful communication of scientific knowledge depended on alignment of

the communication approach with pre-existing communication and knowledge. As research staff and community members interacted and exchanged information, community members developed their own meanings of the research projects which later on became widespread as reality. This new 'hybrid' knowledge or 'reality' therefore facilitated participation or resistance in research.

Taken together, this thesis has identified gaps in community engagement approaches to promote collaborative partnerships, improve ethical research or study acceptability. Even though guidelines present community engagement or collaborative partnerships as the 'right thing to do', the democratic ideals in relation to community engagement may not replace deficit models of engagement in neo-colonial settings but rather coexist. Care therefore needs to be taken to balance between complying with international guidelines and responding to the needs of participating research communities for engaging with researchers.

References

- Adhikari, B., James, N., Newby, G., Von Seidlein, L., White, N. J., Day, N. P. J., Dondorp, A. M., Pell, C. & Phaik Yeong, C. 2016. Community engagement and population coverage in mass anti-malarial administrations: A systematic literature review. *Malaria Journal,* 15**,** 1-21.
- Ahmed, S. M. & Palermo, A.-G. S. 2010. Community engagement in research: Frameworks for education and peer review. *American Journal Of Public Health,* 100**,** 1380-1387.
- Akinwale, O. P., Oyefara, J. O., Adejoh, P. E., Adeneye, A. A., Adeneye, A. K., Musa, Z. A., Oyedeji, K. S. & Sulyman, M. A. 2014. The benefits of using a community-engaged research approach to promote a healthy lifestyle in three Nigerian urban slums. *Southern African Journal of Epidemiology & Infection,* 29**,** 48-50.
- Allman, D. & Ditmore, M. H. 2011. 'Who is helsinki?' Sex workers advise improving communication for good participatory practice in clinical trials. *Health Education Research*, 26(3), 466-475
- Anders, G. (ed.) 2002. *Freedom and insecurity: Civil servants between support networks, the free market and the civil service reform,* Blantyre: Claim.
- Anderson, E. E. & Solomon, S. 2013. Community engagement: Critical to continued public trust in research. *American Journal of Bioethics,* 13**,** 44-46.
- Anderson, E. E., Solomon, S., Heitman, E., Dubois, J. M., Fisher, C. B., Kost, R. G., Lawless, M. E., Ramsey, C., Jones, B., Ammerman, A. & Ross, L. F. 2012. Research ethics education for community-engaged research: A review and research agenda. *Journal of Empirical Research on Human Research Ethics,* 7**,** 3-19.
- Angwenyi, V., Kamuya, D., Mwachiro, D., Kalama, B., Marsh, V., Njuguna, P. & Molyneux, S. 2014. Complex realities: Community engagement for a paediatric randomized controlled malaria vaccine trial in kilifi, kenya. *Trials,* 15**,** 1-28.
- Angwenyi, V., Kamuya, D., Mwachiro, D., Marsh, V., Njuguna, P. & Molyneux, S. 2013. Working with community health workers as ' volunteers' in a vaccine trial: Practical and ethical experiences and implications. *Developing World Bioethics,* 13**,** 38-47.
- Arnstein, S. 1969. A ladder of citizen participation. *JAIP,* 35**,** 216-224.
- Ashforth, A. 2014. When the vampires come for you: A true story of ordinary horror. *Social Research,* 81**,** 851-882.
- Association of Social Anthropologists of the Uk and the Commonwealth. 2011. *Ethical guidelines for good research practice* [Online]. Available: http://ethics.iit.edu/ecodes/node/5498 [Accessed 07 November, 2016.
- Balan Sergiu. No date. M. Foucaults's view on power relations. Available: http://cogito.ucdc.ro/nr_2v2/M.%20FOUCAULT%27S%20VIEW%20ON%20POWER%20RELATIONS.pdf [Accessed 17 December, 2014].
- Bandura, A. 2005. Social cognitive theory: An agentic perspective. *Psychology: The Journal of the Hellenic Psychological Society,* 12**,** 313-333.
- Banks, S., Armstrong, A., Carter, K., Graham, H., Hayward, P., Henry, A., Holland, T., Holmes, C., Lee, A., Mcnulty, A., Moore, N., Nayling, N., Stokoe, A. & Strachan, A. 2013. Everyday ethics in community-based participatory research. *Contemporary Social Science,* 8**,** 263-277.

- Bauer, M. W., Allum, N. & Miller, S. 2007. What can we learn from 25 years of pus survey research? Liberating and expanding the agenda. *Public Understanding of Science,*16**,** 79-95.
- Bazeley, P. 2009. Analysing qualitative data: More than identifying themes™. *Malaysian Journal of Qualitative Research,* 2**,** 6-22.
- Beck, A. 1972. Medical administration and medical research in developing countries: Remarks on their history in colonial east africa. *Bulletin of the History of Medicine* 46**,** 349-352.
- Bermúdez, J. M., Muruthi, B. A. & Jordan, L. S. 2016. Decolonizing research methods for family science: Creating space at the center. *Journal of Family Theory & Review,* 8**,** 192-206.
  Bernard, H. R. 1995. *Research methods in anthropology: Qualitative and quantitative approaches*, Lanham, MD: AltaMira, 2011
- Biruk, C. 2017. Ethical gifts?: An analysis of soap-for-data transactions in malawian survey research worlds. *Medical Anthropology Quarterly,* 31**,** 365-384.
- Blumenthal, D. S. 2011. Current issue: Is community-based participatory research possible? *American Journal of Preventive Medicine,* 40**,** 386-389.
- Bodmer, W. 2010. Public understanding of science: The ba, the royal society and copus. *Notes and records of The Royal Society* [Online]. Available: http://rsnr.royalsocietypublishing.org.
- Boga, M., Davies, A., Kamuya, D., Kinyanjui, S. M., Kivaya, E., Kombe, F., Lang, T., Marsh, V., Mbete, B., Mlamba, A., Molyneux, S., Mulupi, S. & Mwalukore, S. 2011. Strengthening the informed consent process in international health research through community engagement: The kemri-wellcome trust research programme experience. *PLoS Medicine,* 8**,** 1-4.
- Boshoff, N. 2009. Neo-colonialism and research collaboration in central africa. *Scientometrics,* 81**,** 413-434.
- Boulanger, R. F., Stephanie Seidel, Erica Lessem, Lee Pyne-Mercier, Sharon D Williams, Laia Ruiz Mingote, Cherise Scott, Alicia Y Chou, James V Lavery. 2013. Engaging communities in tuberculosis research. *Lancet,* 13**,** 540-545.
- Brett, J., Staniszewska, S., Mockford, C., Herron-Marx, S., Hughes, J., Tysall, C. & Suleman, R. 2014. Mapping the impact of patient and public involvement on health and social care research: A systematic review. *Health Expectations: An International Journal Of Public Participation In Health Care And Health Policy,* 17**,** 637-650.
- Brieland, D. 1971. Community advisory boards and maximum feasible participation. *American Journal Of Public Health,* 61**,** 292-296.
- Britten, N. 1995. Qualitative interviews in medical research. British Medical Association.
- Callahan, D. 2012. *Individual good and common good: A communitarian approach to bioethics*, Oxford University Press.
- Caplan, P. 2000. *Risk revisited*, London : Pluto Press, 2000.
- Carson, L. 2008. Community engagement- beyond tokenism. *Incite,* 29.
- Cathy, A. R. 1993. The ugly scholar: Neo-colonialism and ethical issues in international research. *The American Sociologist***,** 69.
- Chambers, R. 1997. *Whose reality counts?: Putting the first last*, London: Intermediate Technology Publications, 1997.

- Chantler, T., Otewa, F., Onyango, P., Okoth, B., Odhiambo, F., Parker, M. & Geissler, P. W. 2013. Ethical challenges that arise at the community interface of health research: Village reporters' experiences in western kenya. *Developing World Bioethics,* 13**,** 30-37.
- Chimombo, J. 2005. Quantity versus quality in education: Case studies in malawi. *International Review of Education,* 51**,** 155-172.
- Chiweza, A. L. 2007. Local government. *In:* PATEL, N. & SVASAND, L. (eds.) *Government and politics in malawi.* Zomba, Malawi :: Kachere Series.
- Coffey, A. & Atkinson, P. 1996. *Making sense of qualitative data: Complementary research strategies*, Sage, Thousand Oaks (Calif.), 1996.
- Connor, D. 1988. A new ladder of citizen participation. *National Civic Review,* 77.
- Cornwall, A. 2000. *Making a difference? : Gender and participatory development*, Brighton : Institute of Development Studies, University of Sussex, 2000.
- Cornwall, A. & Jewkes, R. 1995. What is participatory research? *Social Science and Medicine,* 41**,** 1667-1676.
- Council for International Organisations of Medical Sciences. 2016. International ethical guidelines for health-related research involving humans, fourth edition
- Cox, L. E., Rouff, J. R., Svendsen, K. H., Markowitz, M. & Abrams, D. I. 1998. Community advisory boards: Their role in aids clinical trials. *Health & Social Work,* 23**,** 290-297.
- Crane, J. 2011. Comment: Scrambling for africa? Universities and global health. *The Lancet,* 377**,** 1388-1390.
- Cyril, S., Smith, B. J., Possamai-Inesedy, A. & Renzaho, A. M. N. 2015. Exploring the role of community engagement in improving the health of disadvantaged populations: A systematic review. *Global Health Action,* 8.
- Davies, S. R. 2011. The rules of engagement: Power and interaction in dialogue events. *Public Understanding of Science,* 22**,** 65-79.
- De Vries, R., Turner, L., Orfali, K. & Bosk, C. 2006. Social science and bioethics: The way forward. *Sociology of Health & Illness,* 28**,** 665-677.
- Department of Health. 2005. Research governance framework for health and social care.Available:http://assets.publishing.service.gov.uk/government/uploads...dh_4122427.pdf [Accessed 21 January, 2019]
- Desmond, N. A., Nyirenda, D., Dube, Q., Mallewa, M., Molyneux, E., Lalloo, D. G. & Heyderman, R. S. 2013. Recognising and treatment seeking for acute bacterial meningitis in adults and children in resource-poor settings: A qualitative study. *PLoS ONE,* 8**,** 1-7.
- Dewalt Kathleen. 2002. *Participant observation: A guide for field workers,* Oxford, Altamira Press.
- Diallo, D. A., Doumbo, O. K., Plowe, C. V., Wellems, T. E., Emanuel, E. J. & Hurst, S. A. 2005. Community permission for medical research in developing countries. *Clinical Infectious Diseases,* 41**,** 255-259.
- Dickert, N. & Sugarman, J. 2005. Ethical goals of community consultation in research. *American Journal of Public Health,* 95**,** 1123-1127.
- Dickert, N., Sugarman, J., 2005. Ethical goals of community consultation in research. *American Journal of Public Health,* 95**,** 1123-1127.
- Dudley, L., Gamble, C., Preston, J., Buck, D., Null, N., Hanley, B., Williamson, P. & Young, B. 2015. What difference does patient and public involvement make and what are its pathways to impact? Qualitative study of patients and researchers from a cohort of randomised clinical trials. *PLoS ONE,* 10**,** 1-17.

- Emanuel, E. J., Wendler, D., Killen, J. & Grady, C. 2004. What makes clinical research in developing countries ethical? The benchmarks of ethical research. *Journal of Infectious Diseases,* 189**,** 930-937.
- Englund, H. 2002. *A democracy of chameleons: Politics and culture in the new malawi*, Stylus Pub Llc.
- Fairhead, J., Leach, M. & Small, M. 2006. Public engagement with science? Local understandings of a vaccine trial in the gambia. *Journal of Biosocial Science,* 38**,** 103-116.
- Farnsworth, S. K., Bose, K., Fajobi, O., Souza, P. P., Peniston, A., Davidson, L. L., Griffiths, M. & Hodgins, S. 2014. Community engagement to enhance child survival and early development in low- and middle-income countries: An evidence review. *Journal of Health Communication,* 19**,** 67-88.
- Federica, F. 2018. Community involvement in biomedical research conducted in the global health context; what can be done to make it really matter? *BMC Medical Ethics, Vol 19, Iss S1, Pp 39-47 (2018)***,** 39.
- Field, J. 2003. *Social capital*, London: Routledge, 2003.
- Fisher, J. A. 2013. Expanding the frame of 'voluntariness' in informed consent: Structural coercion and the power of social and economic context. *Kennedy Institute of Ethics Journal,* 23**,** 355-379.
- Freire, P. 1972. *Pedagogy of the oppressed*, Harmondsworth: Penguin, 1972.
- Gardner, K. & Lewis, D. 1996. *Anthropology, development and the post-modern challenge*, London: Pluto, 1996.
- Gastaldo, D. (ed.) 1997. *'Is health education good for you?Rethinking health education through the concept of bio-power',* London: Newyork, Routledge.
- Gaventa, J. 2006. Finding the spaces for change: A power analysis. Great Britain.
- Gaventa, J., & Cornwall, A., (ed.) 2001. *Power and knowledge,* London: Sage Publications.
- Gaynor, N. 2011. Between citizenship and clientship: The politics of participatory governance in malawi. *Journal of Southern African Studies,* 36**,** 801-816.
- Geissler, P. W. 2011. *Introduction: Studying trial communities: Anthropological and historical inquiries into ethos, politics and economy of medical research in africa*, Berghahn Books.
- Geissler, P. W., Kelly, A., Imoukhuede, B. & Pool, R. 2008. He is now like a brother, i can even give him some blood'- relational ethics and material exchanges in a malaria vaccine trial community in the gambia. *Social Science & Medicine,* 67**,** 696-707.
- Geissler, P. W. & Pool, R. 2006. Editorial: Popular concerns about medical research projects in sub-saharan africa - a critical voice in debates about medical research ethics.*Trop Med Int Health,* 11(7), 975-982
- George, A. S., Mehra, V., Scott, K. & Sriram, V. 2015. Community participation in health systems research: A systematic review assessing the state of research, the nature of interventions involved and the features of engagement with communities. *PLoS ONE,* 10.
- Gillard, S., Simons, L., Turner, K., Lucock, M. & Edwards, C. 1999. Patient and public involvement in the coproduction of knowledge: Reflection on the analysis of qualitative data in a mental health study. *Qual Health Res*, 22(8), 1126-37
- Godoy-Ruiz, P., Mckenzie, K., Cole, D. C. & Lenters, L. 2016. Developing collaborative approaches to international research: Perspectives of new global health researchers. *Global Public Health,* 11**,** 253-275.

- Gondwe, M. & Kavinya, T. 2008. An analysis of malawi's publication productivity. *Malawi Medical Journal,* 20**,** 90-92.
- Goold, S. D., Myers, C. D., Danis, M., Abelson, J., Barnett, S., Calhoun, K., Campbell, E. G., La, H. L., Hammad, A., Rosenbaum, R. P., Kim, H. M., Salman, C., Szymecko, L. & Rowe, Z. E. 2018. Members of minority and underserved communities set priorities for health research. *Milbank Q,* 96**,** 675-705.
- Government of Malawi. 2011. Malawi health sector strategic plan 2011-2016. *In:* MINISTRY OF HEALTH. (ed.). Lilongwe. Available : www.nationalplanningcycles.org/.../Malawi/2_malawi_hssp_2011_-2016_final_docu... [Accessed 21 January, 2019]
- Government of Malawi. 2017, September. Training manual for village health commitees. *In:* MINISTRY OF HEALTH. (ed.). Lilongwe. Available: http://www.strath.ac.uk/media.other.../VHC_TRAINING_MANUAL_sep_202017.p... [Accessed 21 January, 2019]
- Graboyes, M. 2010. Fines, orders, fears and consent? Medical research in east africa, c. 1950s. *Developing World Bioethics,* 10**,** 34-41.
- Graboyes, M. 2014a. Introduction: Incorporating medical research into the history of medicine in east africa. *International Journal of African Historical Studies,* 47**,** 379-398.
- Graboyes, M. 2014b. "The malaria imbroglio": Ethics, eradication, and endings in pare taveta, east africa, 1959-1960. *International Journal of African Historical Studies,* 47**,** 445-471.
- Gudykunst, W. B., Matsumoto, Y., Ting-Toomey, S. & Nishida, T. 1996. The influence of cultural individualism-collectivism, self construals, and individual values on communication styles across cultures. *Human Communication Research,* 22**,** 510-543.
- Hall, S. & Gieben, B. (eds.) 1992. *Formations of modernity,* Oxford: Polity in association with Open University.
- Haynes, E. N., Elam, S., Burns, R., Spencer, A., Yancey, E., Kuhnell, P., Alden, J., Walton, M., Reynolds, V., Newman, N., Wright, R. O., Parsons, P. J., Praamsma, M. L., Palmer, C. D. & Dietrich, K. N. 2016. Community engagement and data disclosure in environmental health research. *Environ Health Perspect,* 124**,** A24-7.
- Heaton, J., Day, J. & Britten, N. 2016. Collaborative research and the co-production of knowledge for practice: An illustrative case study. *Implementation Science,* 11**,** 20.
- Hedgecoe, A. M. 2004. Critical bioethics: Beyond the social science critique of applied ethics. *Bioethics,* 18**,** 120-143.
- Hicks, S. P., Duran, B. D., Wallerstein, N. D., Avila, M. D., Belone, L. P., Lucero, J. P., Magarati, M. P., Mainer, E., Martin, D., Muhammad, M. P., Oetzel, J. P., Pearson, C. P., Sahota, P. P., Simonds, V. S. M. S., Sussman, A. P. M., Tafoya, G. M. P. H. & Hat, E. W. J. D. 2012. Evaluating community-based participatory research to improve community-partnered science and community health. *Progress in Community Health Partnerships,* 6**,** 289-99.
- Hokkanen, M. 2012. Imperial networks, colonial bioprospecting and burroughs wellcome & co.: The case of strophanthus kombe from malawi (1859-1915). *Social History of Medicine,* 25**,** 589-607.
- Hokkanen, M. 2015. The government medical service and british missions in colonial malawic. 1891-1940. *In:* GREENWOOD, A. (ed.) *Beyond the state: The colonial medical service in british africa.* Manchester, England: Manchester University Press.

- Holzer, J. K., Ellis, L. & Merritt, M. W. 2015. Why we need community engagement in medical research. *Journal of Investigative Medicine (Decker Publishing),* 62**,** 851-855 5p.
- House of Lords 2000. Science and technology-third report. Science and Technology committee publications. Available: https://publications.parliament.uk/pa/id199900/idselect/idsctech/38/3801.htm [Accessed 14 February, 2016]
- Huggan, G. 1997. *The neocolonialism of postcolonialism: A cautionary note*.
- Hughes, R. C. 2014. Justifying community benefit requirements in international research. *Bioethics,* 28**,** 397-404.
- Ilan, K. 2002. The devil's in the theory: A critical assessment of robert chambers' work on participatory development. *Third World Quarterly***,** 101.
- International Aids Vaccine Initiative. 2012. Insights: The community advisory board: An evolving approach to cabs. Available: htttp://www.iavi.org/publications [Accessed 28 October 2014].
- Ives, J., Damery, S. & Redwod, S. 2013. Ppi, paradoxes and plato: Who's sailing the ship? *Journal Of Medical Ethics,* 39**,** 181-185.
- Johnson, D. S., Bush, M. T., Brandzel, S. & Wernli, K. J. 2016. The patient voice in research: Evolution of a role. *Research Involvement and Engagement,* 2**,** 6.
- Kamuya, D. M., Marsh, V., Kombe, F. K., Geissler, P. W. & Molyneux, S. C. 2013. Engaging communities to strengthen research ethics in low-income settings: Selection and perceptions of members of a network of representatives in coastal kenya. *Developing World Bioethics,* 13**,** 10-20.
- Kamuya, D. M., Marsh, V., Parker, M., Molyneux, S., Njuguna, P. & Munywoki, P. 2014. "When they see us, it's like they have seen the benefits!": Experiences of study benefits negotiations in community-based studies on the kenyan coast. *BMC Medical Ethics,* 15.
- Kamuya, D. M., Molyneux, C. S. & Theobald, S. 2017. Gendered negotiations for research participation in community-based studies: Implications for health research policy and practice. *BMJ Global Health,* 2.
- Kawulich, B. B. 2005. Participant observation as a data collection method. *2005,* 6 (2). Available: www.qualitative-research.net [Accessed 15 June, 2015]
- Khodyakov, D., Stockdale, S., Jones, F., Ohito, E., Jones, A., Lizaola, E. & Mango, J. 2012. An exploration of the effect of community engagement in research on perceived outcomes of partnered mental health services projects(). *Society And Mental Health,* 1**,** 185-199.
- Khodyakov, D., Stockdale, S., Jones, A., Mango, J., Jones, F., Lizaola, E., 2012. On measuring community participation in research. *Health Education & Behaviour,* 40**,** 346-354.
- King, M. & King, E. 2007. *The story of medicine and disease in malawi,* Blantyre, Montfort Press.
- Kingori, P. 2015. The 'empty choice': A sociological examination of choosing medical research participation in resource-limited sub-saharan africa. *Current Sociology,* 63**,** 763-778.
- Kingori, P., De Vries, R. & Orfali, K. 2013. Special issue introduction: Bioethics in the field. *Social Science & Medicine*.
- Kirigia, J. M., Kathyola, D. D., Muula, A. S. & Ota, M. M. O. 2015. National health research system in malawi: Dead, moribund, tepid or flourishing? *BMC Health Services Research,* 15**,** 126-126.

- Korrie, D. K. 1995. Participatory appraisal and education for empowerment? *PLA Notes*. Available:pubs.iied.org/pdfs/G01595.pdf [Accessed 17 August, 2018]
- Lairumbi, G. M., Parker, M. & Fitzpatrick, R. 2012. Forms of benefit sharing in global health research undertaken in resource poor settings: A qualitative study of stakeholders' views in kenya. *Philosophy, Ethics, and Humanities in Medicine,* 7**,** 1-8.
- Lang, T. & Siribaddana, S. 2012. Clinical trials have gone global: Is this a good thing?. *PLoS Med*, 9 (6): e1001228
- Larner, A. J. No date. Medical aspects of dr livingstone's zambesi expedition, 1858-1864. Available: https:www.researchgate.net/…265847926_MEDICAL ASPECTS_OF_DR_LIVINGSTONE%27S_ZAMBESI_EXPEDITION_1858-1864 [Accessed 13 February, 2019]
- Laurie Ackerman, G. & Karusa, K. 2012. Lessons learnt from promising practices in community engagement for the elimination of new hiv infections in children by 2015 and keeping their mothers alive: Summary of a desk review. *Journal of the International AIDS Society , Vol 15, Iss 4(Suppl 2), Pp 1-8 (2012)***,** 1.
- Lavery, J. V., Tindana, P. O., Scott, T. W., Harrington, L. C., Ramsey, J. M., Ytuarte-Nuã±Ez, C. & James, A. A. 2010. Opinion: Towards a framework for community engagement in global health research. *Trends in Parasitology,* 26**,** 279-283.
- Lee, J. A. 2013. "Can you hear me now?": Making participatory governance work for the poor. *Harvard Law & Policy Review,* 7**,** 405-441.
- Long, N. 1999. The multiple optic of interface analysis (working title). *UNESCO Background Paper on Interface Analysis, October 1999.* Wageningen University, Netherlands.
- Lupton, D. 1997. 'Foucault and the medicalisation critique'. *In:* PETERSON A AND BUNTON R. (ed.) *Foucault, health and medicine.* London: Routledge.
- Lwanda, J. 2007. *Scotland, malawi and medicine: Livingstone's legacy, i presume? An historical perspective*. *Scottish medical journal,* 52(3):36-44
- Lwanda, J. L. 2005. *Politics, culture and medicine in malawi: Historical continuities and ruptures with special reference to hiv/aids*, University of Malawi, Religious and Theological Studies Department.
- Lwin, K. M., Cheah, P. Y., Cheah, P. K., White, N. J., Day, N. P. J., Nosten, F. & Parker, M. 2014. Motivations and perceptions of community advisory boards in the ethics of medical research: The case of the thai-myanmar border. *BMC Medical Ethics,* 15.
- Macqueen, K. M., Mclellan, E., Metzger, D. S., Kegeles, S., Strauss, R. P., Scotti, R., Blanchard, L. & Trotter, R. T. 2001. What is community? An evidence-based definition for participatory public health. *American Journal Of Public Health,* 91**,** 1929-1938.
- Magolowondo, A. 2007. Government and politics in malawi. *In:* PATEL, N. & SVASAND, L. (eds.). Zomba, Malawi : Kachere Series.
- Malawi Communications Regulatory Authority. 2015. National survey on access to and usage of ict services in malawi. Available: http://www.macra.org.mw/?page_id=354 [Accessed 21 December, 2016].
- Manda-Taylor, L. 2013. Establishing community advisory boards for clinical trial research in malawi: Engendering ethical conduct in research. *Malawi Medical Journal,* 25**,** 96.
- Manda, D. 2002. Malawi's transition from neo-colonial rule: From a 'culture of silence to a clamour of voices?'. Available:

researchspace.ukzn.ac.uk/bitstream/handle.1043/3754/Manda_Domuka_Lucinda [Accessed 16 November, 2017]
- Marsh, V., Kamuya, D., Rowa, Y., Gikonyo, C. & Molyneux, S. 2008a. Beginning community engagement at a busy biomedical research programme: Experiences from the kemri cgmrc-wellcome trust research programme, kilifi, kenya. *Social Science & Medicine,* 67**,** 721-733.
- Marsh, V., Kamuya, D., Rowa, Y., Gikonyo, C. & Molyneux, S. 2008b. Beginning community engagement at a busy biomedical research programme: Experiences from the kemri cgmrc-wellcome trust research programme, kilifi, kenya. *Social Science & Medicine (1982),* 67**,** 721-733.
- Marsh, V. M., Kamuya, D. K., Parker, M. J. & Molyneux, C. S. 2011. Working with concepts: The role of community in international collaborative biomedical research. *Public Health Ethics,* 4**,** 26-39.
- Marsh, V. M., Kamuya, D. M., Mlamba, A. M., Williams, T. N. & Molyneux, S. S. 2010. Experiences with community engagement and informed consent in a genetic cohort study of severe childhood diseases in kenya. *BMC Medical Ethics,* 11.
- Masiye, F., Kass, N., Hyder, A., Ndebele, P. & Mfutso-Bengo, J. 2008. Why mothers choose to enrol their children in malaria clinical studies and the involvement of relatives in decision making: Evidence from malawi. *Malawi Medical Journal,* 20**,** 50.
- Mccallum, A. D., Nyirenda, D., Lora, W., Khoo, S. H., Sloan, D. J., Mwandumba, H. C., Desmond, N. & Davies, G. R. 2016. Perceptions of research bronchoscopy in malawian adults with pulmonary tuberculosis: A cross-sectional study. *PLoS ONE,* 11**,** e0165734.
- Mccloskey, D. 2011. Community engagement: Definations and defining concepts from the literature. *In:* CONSORTIUM, C. A. T. A. A. (ed.) *Principles of community engagement- second edition.* NIH.
- Mccracken, J. 2012. *A history of malawi, 1859-1966,* Woodbridge, UK, James Currey.
- Merriam, S. B. & Tisdell, E. J. 2015. *Qualitative research. [electronic book] : A guide to design and implementation*,: Wiley, 2015
- Mfutso-Bengo, J., Manda-Taylor, L, Jumbe, V, Kazanga, I, Masiye, F., (ed.) 2014. *Malawi: Bioethics development,* Netherlands: Springer.
- Mfutso-Bengo, J., Masiye, F., Molyneux, M., Ndebele, P. & Chilungo, A. 2008a. Why do people refuse to take part in biomedical research studies? Evidence from a resource-poor area. *Malawi Medical Journal,* 20**,** 57.
- Mfutso-Bengo, J., Ndebele, P., Jumbe, V., Mkunthi, M., Masiye, F., Molyneux, S. & Molyneux, M. 2008b. Why do individuals agree to enrol in clinical trials? A qualitative study of health research participation in blantyre, malawi. *Malawi Medical Journal,* 20**,** 37.
- Mikesell, L., Bromley, E. & Khodyakov, D. 2013. Ethical community-engaged research: A literature review. *American Journal of Public Health,* 103**,** 7-14.
- Miller, J. 1983. Scientific literacy: A conceptual and empirical review. *Daedulus,* 112**,** 29-48.
- Milton, B., Attree, P., French, B., Povall, S., Whitehead, M., Popay, J., Milton, B., Attree, P., French, B., Povall, S., Whitehead, M. & Popay, J. 2011. The impact of community engagement on health and social outcomes: A systematic review. *Community Development Journal,* 47**,** 316.

- Ministry of Health. 2011. Malawi health sector strategic plan 2011-2016. Available: http://www.nationalplanningcycles.org/sites/default/files/country_docs/Malawi/2_malawi_hssp_2011_-2016_final_document_1.pdf [Accessed 22 December, 2016].
- Ministry of Health. 2012. National health research agenda 2012-2016. Ministry of Health, Lilongwe.
- Minkler, M. 2005. Community-based research partnerships: Challenges and opportunities. *Journal of Urban Health : Bulletin of the New York Academy of Medicine,* 82**,** 3-12.
- Molyneux, S. & Geissler, P. W. 2008. Ethics and the ethnography of medical research in africa. *Social Science & Medicine,* 67**,** 685-695.
- Molyneux, S., Kamuya, D. & Marsh, V. 2010. Community members employed on research projects face crucial, often under-recognized, ethical dilemmas. *American Journal of Bioethics,* 10**,** 24-26.
- Morin, S. F., Maiorana, A., Koester, K. A., Sheon, N. M. & Richards, T. A. 2003. Community consultation in hiv prevention research: A study of community advisory boards at 6 research sites. *Journal of Acquired Immune Deficiency Syndromes,* 33**,** 513-520.
- Morin, S. F., Morfit, S., Maiorana, A., Aramrattana, A., Goicochea, P., Mutsambi, J. M., Robbins, J. L. & Richards, T. A. 2008. Building community partnerships: Case studies of community advisory boards at research sites in peru, zimbabwe, and thailand. *Clinical Trials,* 5**,** 147-156 10p.
- Mosse, D. 2006. Anti-social anthropology? Objectivity, objection, and the ethnography of public policy and professional communities. *The Journal of the Royal Anthropological Institute***,** 935.
- Muela, S. H., Ribera, J. M., Mushi, A. K. & Tanner, M. 2002. Medical syncretism with reference to malaria in a tanzanian community. *Soc Sci Med,* 55(3), 403-13
- Musesengwa, R. & Chimbari, M. J. 2015. Community engagement practices in southern africa: Review and thematic synthesis of studies done in botswana, zimbabwe and south africa. *Acta Tropica*.
- Muula, A. S. & Broadhead, R. L. 2001. The first decade of the malawi college of medicine: A critical appraisal. *Tropical Medicine & International Health,* 6**,** 155.
- Muula, A. S., Mulwafu, W., Chiweza, D. & Mataya, R. 2016. Reflections on the first twenty-five years of the university of malawi college of medicine. *Malawi Medical Journal: The Journal Of Medical Association Of Malawi,* 28**,** 75-78.
- Mwalubunju, O. 2007. Civil society. *In:* PATEL, N. & SVASAND, L. (eds.) *Government and politics in malawi.* Zomba, Malawi: Kachere Series.
- Mwendera, C. A., De Jager, C., Longwe, H., Hongoro, C., Mutero, C. M. & Phiri, K. S. 2017. Malaria research in malawi from 1984 to 2016: A literature review and bibliometric analysis. *Malaria Journal*, 16:264
- Nachega, J. B., Uthman, O. A., Ho, Y.-S., Lo, M., Anude, C., Kayembe, P., Wabwire-Mangen, F., Gomo, E., Sow, P. S., Obike, U., Kusiaku, T., Mills, E. J., Mayosi, B. M. & Ijsselmuiden, C. 2012. Current status and future prospects of epidemiology and public health training and research in the who african region. *International Journal of Epidemiology,* 41**,** 1829-1846.
- Nakibinge, S., Maher, D., Katende, J., Kamali, A., Grosskurth, H. & Seeley, J. 2009. Community engagement in health research: Two decades of experience from a research project on hiv in rural uganda. *Top Med Int Health,* 14**,** 190-5.
- National Co-Ordinating Centre for Public Engagement. 2010. Available: http://www.publicengagement.ac.uk [Accessed 29 July 2014.

- National Malaria Control Programme and Icf. 2018. Malawi malaria indicator survey 2017. Lilongwe, Malawi and Rockville, Maryland, USA: NMCP and ICF.
- National Statistics Office & Icf Macro 2011. *Malawi demographic and health survey 2010,* Zomba, Malawi, NSO & ICF Macro.
- National Statistics Office. 2008. Population and housing census main report. Zomba: National Statistics Office.
- National Statistics Office. 2012. Third intergrated household survey 2010-2011. Zomba National Statistics Office.
- Neill, D. 2009. Paul ehrlich's colonial connections: Scientific networks and sleeping sickness drug therapy research, 1900-1914. *Social History of Medicine,* 22**,** 61-77.
- Neill, D. 2012. Networks in tropical medicine: Internationalism, colonialism and the rise of medical specialty. Stanford: Stanford University Press.
- Newman, S. D., Andrews, J. O., Magwood, G. S., Jenkins, C., Cox, M. J. & Williamson, D. C. 2011. Community advisory boards in community-based participatory research: A synthesis of best processes. *Preventing Chronic Disease,* 8**,** 1.
- Nice. No date. Community engagement: Final scope. Available: https://www.google.com/search?site=&source=hp&q=community+engagement+and+community+development+approaches+to+health+improvement+scope&oq=community+engagement+and+community+development+approaches+to+health+improvement+scope&gs_l=psy-ab.12...2985.2985.0.4499.3.2.0.0.0.0.304.563.2-1j1.2.0....0...1.2.64.psy-ab..1.1.303.6..35i39k1.J4YVGrfx91A [Accessed 4 August, 2017].
- Nimegeer, A., Farmer, J., Munoz, S. A. & Currie, M. 2006. Community participation for rural healthcare design: Description and critique of a method. *Health & Social Care in the Community,* 24**,** 175-183.
- Nkrumah, K. 1966. *Neo-colonialism: The last stage of imperialism,* New York, International Publishers.
- Northway, R., Hurley, K., O'connor, C., Thomas, H., Howarth, J., Langley, E. & Bale, S. 2014. Deciding what to research: An overview of a participatory workshop. *British Journal of Learning Disabilities,* 42**,** 323-327.
- Ntshanga, S. P., Ngcobo, P. S. & Mabaso, M. L. H. 2009. Establishment of a community advisory board (cab) for tuberculosis control and research in the inanda, ntuzuma and kwamashu (ink) area of kwazulu-natal, south africa. *Health Policy,* 95**,** 211-215.
- Nwaka, S., Ridley, R. G., Ilunga, T. B., Da Silva, J. S., Verde, E. R., Hackley, D., De Vré, R. & Mboya-Okeyo, T. 2010. Developing andi: A novel approach to health product r&d in africa. *PLoS Medicine,* 7.
- Nyika, A., Chilengi, R., Ishengoma, D., Mtenga, S., Thera, M. A., Sissoko, M. S., Lusingu, J., Tiono, A. B., Doumbo, O., Sirima, S. B., Lemnge, M. & Kilama, W. L. 2010. Engaging diverse communities participating in clinical trials: Case examples from across africa. *Malaria Journal,* 9.
- Nyirenda, D., Makawa, T. C., Chapita, G., Mdalla, C., Nkolokosa, M., O'byrne, T., Heyderman, R. & Desmond, N. 2016. Public engagement in malawi through a health-talk radio programme umoyo nkukambirana: A mixed-methods evaluation. *Public Understanding of Science*.22(2):p.229
- Nyirenda, D., Sariola, S., Gooding, K., Phiri, M., Sambakunsi, R., Moyo, E., Bandawe, C., Squire, B. & Desmond, N. 2017. 'We are the eyes and ears of researchers and community': Understanding the role of community advisory groups in

representing researchers and communities in malawi. *Developing World Bioethics*.00:1-9

- O'mara-Eves, A., Brunton, G., Oliver, S., Kavanagh, J., Jamal, F. & Thomas, J. 2015. The effectiveness of community engagement in public health interventions for disadvantaged groups: A meta-analysis. *BMC Public Health,* 15**,** 1-23.
- Okello, G., Jones, C., Bonareri, M., Ndegwa, S. N., Mcharo, C., Kengo, J., Kinyua, K., Dubeck, M. M., Halliday, K. E., Jukes, M. C. H., Molyneux, S. & Brooker, S. J. 2013. Challenges for consent and community engagement in the conduct of cluster randomized trial among school children in low income settings: Experiences from kenya. *Trials,* 14**,** 1-11.
- Parry Sarah., F. W., Cunningham-Burley Sarah., Marks Nicola., 2012. Heterogenous agendas around stem cell research: The case of maintaining plasticity. *Science and Technology studies,* 25**,** 61-80.
- Participants in the Community Engagement and Consent Workshop, K., Kenya, March, 2011., 2013. Consent and community engagement in diverse research contexts: Reviewing and developing research and practice. *Journal Of Empirical Research On Human Research Ethics: JERHRE.*
- Patton, M. Q. 2002. *Qualitative research and evaluation methods*, Los Angeles : SAGE, 2013.
- Phiri, D. D. 2004. *History of malawi : From earliest times to the year 1915,* Blantyre [Malawi], Christian Literature Association in Malawi.
- Phiri, D. D. 2010. *History of malawi* Blantyre, College Publishing Compony.
- Pool, R. & Geissler, W. 2005. *Medical anthropology*, Maidenhead: Open University Press, 2005.
- Pratt, B. & Loff, B. 2014. A comparison of justice frameworks for international research. *Journal Of Medical Ethics*.
- Pratt, B., Lwin, K. M., Zion, D., Nosten, F., Loff, B. & Cheah, P. Y. 2015. Exploitation and community engagement: Can community advisory boards successfully assume a role minimising exploitation in international research? *Developing World Bioethics,* 15**,** 18-26.
- Quinn, S. C. 2004. Ethics in public health research: Protecting human subjects: The role of community advisory boards. *Health Policy and Ethics Forum,* 94.
- Quinn, S. C., Kass, N. E. & Thomas, S. B. 2013. Building trust for engagement of minorities in human subjects research: Is the glass half full, half empty, or the wrong size? *American Journal Of Public Health,* 103**,** 2119-2121.
- Reddy, P., Sifunda, S., James, S., Naidoo, N. & Buchanan, D. 2010. The role of community advisory boards in health research: Divergent views in the south african experience. *Sahara J,* 7**,** 2-8.
- Reeves, S., Kuper, A. & Hodges, B. D. 2008. Qualitative research methodologies: Ethnography. *BMJ: British Medical Journal (International Edition),* 337**,** 512.
- Reynolds, L. & Sariola, S. 2018. The ethics and politics of community engagement in global health research. *Critical Public Health,* 28**,** 257-268.
- Rhodes, R. 2010. Rethinking research ethics. *The American Journal Of Bioethics: AJOB,* 10**,** 19-36.
- Rifkin, S. B. 2014. Examining the links between community participation and health outcomes: A review of the literature. *Health Policy and Planning,* 29**,** ii98-ii106.
- Ritchie, J. & Lewis, J. E. 2003. *Qualitative research practice : A guide for social science students and researchers*, London : SAGE, 2003.

- Robert, C. H. 2012. Individual risk and community benefit in international research. *Journal Of Medical Ethics*, 626.
- Ross, A. C. 2009. *Colonialism to cabinet crisis: A political history of malawi,* Zomba, Malawi, Kachere Series.
- Ross, L. F., Loup, A., Nelson, R. M., Botkin, J. R., Kost, R., Smith, G. R. & Gehlert, S. 2010a. Human subjects protections in community-engaged research: A research ethics framework. *Journal of Empirical Research on Human Research Ethics,* 5**,** 5-17.
- Ross, L. F., Loup, A., Nelson, R. M., Botkin, J. R., Kost, R., Smith, G. R. & Gehlert, S. 2010b. Nine key functions for a human subjects protection program for community-engaged research: Points to consider. *Journal of Empirical Research on Human Research Ethics,* 5**,** 33-47.
- Salimi, Y., Malekafzali, H., Majdzadeh, R., Shahandeh, K., Loori, N., Kheiltash, A., Jamshidi, E. & Frouzan, A. S. 2012. Is community-based participatory research (cbpr) useful? A systematic review on papers in a decade. *International Journal of Preventive Medicine,* 3**,** 386-393.
- Scott, J. C. 1997. *Weapons of the weak. [electronic book] : Everyday forms of peasant resistance*, New Haven : Yale University Press, [1985].
- Shagi, C., Vallely, A., Kasindi, S., Chiduo, B., Desmond, N., Soteli, S., Kavit, N., Vallely, L., Lees, S., Hayes, R. & Ross, D. 2008. A model for community representation and participation in hiv prevention trials among women who engage in transactional sex in africa. *AIDS Care,* 20**,** 1039-1049.
- Sharma, M. 2015. Helping or hindering? Some ethical implications of global health work: Comment on a global health case: Questioning our contributions by kelly anderson. *Journal of Bioethical Inquiry,* 12**,** 157-158.
- Shubis, K., Juma, O., Sharifu, R., Burgess, B. & Abdulla, S. 2009. Challenges of establishing a community advisory board (cab) in a low-income, low-resource setting: Experiences from bagamoyo, tanzania. *Health Research Policy and Systems,* 7.
- Sieber, J. E. 2010. Introduction: Points to consider in community-engaged research. *Journal of Empirical Research on Human Research Ethics,* 5**,** 3-4.
- Slevin, K., Upkong, M. & Helse, L. No date. Community engagement in hiv prevention trials: Evolution of the field and opportunities for growth. *aids2031 background paper* [Online]. Available: Http://www.path.org/publications/files/aids2031 [Accessed 27 October, 2014].
- Smith P & Morrow R. 1996. *Field trials of health interventions: A toolbox*, Oxford University Press.
- South, J. & Phillips, G. 2014. Evaluating community engagement as part of the public health system. *Journal Of Epidemiology And Community Health*.
- Staley, K. 2009. Exploring impact; public involvement in nhs, public health and social care research. Available: http://www.invo.org.uk/posttypepublication/exploring-impact-public-involvement-in-nhs-public-health-and-social-care-research/ [Accessed 13 July, 2017].
- Staley, K. 2015. Is it worth doing? Measuring the impact of patient and public involvement in research. *Research Involvement and Engagement,* 1**,** 1-10.
- Stein D, V. C. 2012. *Understanding 'theory of change' in international development: A review of existing knowledge,* London, London School of Economics; .
- Strauss, R. P., Sengupta, S., Quinn, S. C., Goeppinger, J., Spaulding, C., Kegeles, S. M. & Millett, G. 2001. The role of community advisory boards: Involving communities in the informed consent process. *American Journal of Public Health,* 91.

- Swidler, A. & Watkins, S. C. 2009. Teach a man to fish: The sustainability doctrine and its social consequences. *World Development,* 37**,** 1182-1196.
- Tambulasi R, K. R. 2005. Can african feet divorce western shoes? The case of 'ubuntu' and democratic good governance in malawi. *Nordic Journal of African Studies* 14**,** 147-161.
- The National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research. 1979. The belmont report. *In:* OFFICE, U. G. P. (ed.). Washington, DC.
- The Royal Society. 1985. The public understanding of science. Available: https://royalsociety.org/ [Accessed 30 March, 2015].
- The World Bank. 2016. *Malawi-the country at a glance* [Online]. Available: http://www.worldbank.org/en/country/malawi [Accessed 27 June, 2016.
- Tilley, H. 2014. Conclusion: Experimentation in colonial east africa and beyond. *The International Journal of African Historical Studies,* 47**,** 495.
- Tindana, P., De Vries, J., Campbell, M., Littler, K., Seeley, J., Marshall, P., Troyer, J., Ogundipe, M., Alibu, V. P., Yakubu, A. & Parker, M. 2015. Community engagement strategies for genomic studies in africa: A review of the literature. *BMC Medical Ethics,* 16.
- Tindana, P., Singh, J., Tracy, S., Upshur, R., Daar, A., Singer, P., Frohlich, J., 2007. Grand challenges in global health: Community engagement in research in developing countries *PLoS Medicine,* 4.
- Tindana., R. L., Boulanger R., Bandewar, S., Aborigo, R., Hodgson A., Kolopack, P., Lavery, J., 2011. Alligning community engagement with traditional authority structures in global health research: A case study from northern ghana. *American Journal of Public Health,* 101.
- Turshen, M. 1989. *The politics of public health*, London: Zed, 1989.
- U205 Course Team. 1985. *Studying health and disease*, The Open University
- Ukpong, M. a. P. 2009. Oral tenofovir controversy ii: Voices from the field: A series of reports of the oral tenofovir trials from the perspectives of active community voices engageg on the field in cambodia, cameroon, nigeria, thailand and malawi. Available: http://www.nhvmas-ng.org/publications/TDF2.pdf [Accessed 15 February, 2019].
- United Nations Development Programme. 2015. Human development reports-malawi. Available: http://hdr.undp.org/en/countries/profiles/MWI [Accessed 21 December 2016].
- Vallely, A., Shagi, C., Kasindi, S., Desmond, N., Lees, S., Chiduo, B., Hayes, R., Allen, C. & Ross, D. 2007. The benefits of participatory methodologies to develop effective community dialogue in the context of a microbicide trial feasibility study in mwanza, tanzania. *BMC Public Health***,** 133.
- Vaughan, M. 2013. *Curing their ills. [electronic book] : Colonial power and african illness*, Somerset : Wiley, 2013.
- Veneklasen, L., Vallerie Miller, Debbie Budlender,. 2002. Power and empowerment. *PLA Notes* [Online], 43.
- Wa Health. 2007. Wa health consumer carer and community engagement framework for health services, hospitals and wa health following consultation accross wa health Available: http://www.health.wa.gov.au/hrit/docs/publications [Accessed 28 October 2014].
- Walsh, A., Matthews, A., Manda-Taylor, L., Brugha, R., Mwale, D., Phiri, T. & Byrne, E. 2018. The role of the traditional leader in implementing maternal, newborn and child health policy in malawi.

- Wellcome Trust. East of the sun and west of the moon: Is measuring the impact of public engagement with science a fantasy? Available: www.wellcome.ac.uk/about-us/publications/Reports/public-engagement [Accessed 24 April, 2014].
- White, L. C. 1984. 'Tribes' and the aftermath of the chilembwe rising. *African Affairs,* 83**,** 511-541.
- Whittaker, M. & Smith, C. 2015. Reimagining malaria: Five reasons to strengthen community engagement in the lead up to malaria elimination. *Malaria Journal,* 14.
- Whyte, S. 2011. Writing knowledge and acknowledgement. *In:* GEISSER, P. (ed.) *Evidence, ethos and experiment: The anthropology and history of medical research in africa.* Berghahn Books.
- Wickens, C. M. & Sandlin, J. A. 2007. Literacy for what? Literacy for whom? The politics of literacy education and neocolonialism in unesco- and world bank-sponsored literacy programs. *Adult Education Quarterly: A Journal of Research and Theory,* 57**,** 275-292.
- World Bank. 2014. *World development indicators* [Online]. Available: http://databank.worldbank.org/data/views/reports [Accessed 26 June, 2013.
- World Health Organisation. 1978. Declaration of alma ata: International conference on primary health care, alma-ata, ussr. Available: http://www.searo.who.int/linkfiles/Health_Systems_declaration_almaata.pdf.
- World Health Organisation. 2014. *Health information, research, evidence and knowledge* [Online]. Available: http://www.aho.afro.who.int/profiles_information/index.php/Malawi:Health_information,_research,_evidence_and_knowledge [Accessed 27 June, 2016.
- World Health Organisation. 2015. *Malawi: Who statistical profile* [Online]. Available: http://www.who.int/gho/countries/mwi.pdf?ua=1 [Accessed 27 June, 2016.
- World Health Organisation. 2016a. *Global health observatory country views: Malawi statistics summary* [Online]. Available: http://apps.who.int/gho/data/node.imr [Accessed 22 December, 2016.
- World Health Organisation. 2016b. *Malawi: Health research* [Online]. Available: http://www.aho.afro.who.int/profiles_information/index.php/Malawi:Health_research [Accessed 05 January, 2017.
- World Health Organisation. 2016c. *World health statistics 2016: Monitoring health for sdgs* [Online]. Available: http://www.who.int/gho/publications/world_health_statistics/2016/Annex_A/en/ [Accessed 21 December, 2016.
- Yarborough, M., Edwards, K., Espinoza, P., Geller, G., Sarwal, A., Sharp, R. & Spicer, P. 2013. Relationships hold the key to trustworthy and productive translational science: Recommendations for expanding community engagement in biomedical research. *CTS: Clinical & Translational Science,* 6**,** 310-313.
- Zaharlic Amy, G. J. 2005. Ethnographic research. *In:* J. FLOOD, D. L., J. R. SQUIRE, AND J. M. JENSEN, EDS. (ed.) *Methods of research on teaching the english language arts.* Mahwah, N.J.: Lawrence Erlbaum Associates.

Appendices

Appendix 1: Definitions of community engagement

Author	Definition
Ahmed, 2010	*A process of inclusive participation that supports mutual respect of values, strategies and actions for **authentic partnership** of people affiliated by geographical location, shared interest or similar circumstances to address issues affecting community wellbeing (Ahmed and Palermo, 2010)*
Carnegie, 2006	*Community engagement describes the **collaboration** between institutions of higher education and their larger communities for the mutually beneficial exchange of knowledge and resources in a context of partnership and reciprocity* (Carson, 2008).
CDC/NIH	*The process of working **collaboratively** with and through groups of people affiliated by geographical proximity, special interest, or similar situations to address issues affecting the wellbeing of those people (McCloskey, 2011)*
WA Health, 2007	*'The process by which **the aspirations, concerns, needs and values of citizens and communities are incorporated in government, non-government and private sector decision making, planning service delivery and evaluation*** (WA Health., 2007).
NICE, 2010	*'The process of **getting communities involved in decisions that affect them including planning, development, and management of services, as well as activities which aim to improve health or reduce health inequalities'** (National Co-ordinating Centre for Public Engagement, 2010).*

Appendix 2: Socio demographic details of workshop participants

	Workshop-rural	Workshop-urban	Total
Gender			
Male	11	10	21
Female	10	6	16
Age			
20-30	7	0	7
31-40	5	6	11
41-50	7	4	11
51-60	2	3	5
61-70	0	3	3
Education			
Primary education	15	4	19
Secondary education	6	5	11
Post-secondary	0	7	7
Profession			
Business	0	3	3
Farmer	19	1	20
Community Health Worker		5	5

Appendix 3: Topic guide for SSI

Engage study

Topic guide for research participants/non-research participant V.2

Experiences of research

1. Before this research project, did you have knowledge of any health research project? What was the research about? How did you know about it?
   Kafukufuku uyu asanabwere, mungandofotokoreko za kafukufuku wina aliyense wazaumoyo amene inu munanvako? Anali kafukufuku wachani? Inu munadziwa bwanji za kafukufuku ameneyu?

2. Can you please share any past experiences you have had in research? how about your close friends& family? *Munganditokoreko za kafukufuku wina ali yense amene munalowako? Nanga abale anu analowako mukafukufuku?*
   a) when was this? *Ndi liti?*
   b) where did it take place? *Kafukufuku ameneyu amachitika kuti?*
   c) How did you/they hear about it?
      Kodi inu munanva bwanji za kafukufuku?
   d) What were you/ they expected to do?
      Nanga kodi inu mumayenera kupanga chani?
   e) What made you/them refuse or enrol in the study?
      Inu chifukwa chiyani munalowa mu kafukufuku ameneyu? Nanga chifukwa chani munakana mu kafukufuku ameneyu?

f) Did you/they have any concerns? How did you/they raise the concerns? How were they resolved?

Kodi inu munali ndi nkhawa ili yonse? nanga kodi munafotozera ndani nkhwawa zanu?

g) How does this experience influence your perception of research/ researchers?

Kodi kafukufuku ameneyu amakhudza bwanji momwe inu mumawonera kafukufuku wazaumoyo?

Understanding of health research

3. What is your understanding of health research? How did you know about this?

kodi kafukufuku wazaumoyo mumamunvetsetsa bwanji? Inu munadziwa bwanji za izi?

Communication of research project

4. How did you hear about the .....study? (Probe: community/ hospital based sensitizations meetings, CAGs, research staff). *Kodi inu munadziwa bwanji zakafukufuku wa .....*

a) Who told you about it? Who brought the letters? *Anakufotokozerani ndani?*

b) What did they tell you? *Anakufotokozerani bwanji/ motani*?

5. How did you feel when you heard that your child is being invited in the research? Why did you feel that way? *Kodi uthenga okuti mwana wanu akupemhedwa kuti alowe nawo mu kafukufuku wa.....mwaulandira bwanji?*

6. What did you think about the channel of communication/ information about the research? (Probe: personnel, relevance, effectiveness). *Kodi ubwino kapena kuyipa kwa njira zimene zinagwiritsidwa ntchito kuti uthenga wa kafukufuku ukupezeni ndikotani ?*
    a) What was important to you to know more about the research? *Ndi zinthu ziti zimene zinali zofunika kuti inu mudziwe?*
    b) Why was is important to know about that? *Chifukwa chani munafuna kudziwa zimenezi?*
    c) What could be done to improve communication about the research? Why do you say so? *Kodi tipange bwanji kuti tithe kufikira anthu ndi uthenga wakafukufuku? Chifukwa chiyani mukuteno?*

Understanding of present study

7. Can you please explain to me about the study that you are involved in? *Mungandifotokozereko za kafukufuku wa.....*
    a) Why it is being done? *Chifukwa chiyani kafukufukuyu akuchitika?*
    b) What is it going to involve? *Chizichitika ndi chani mukafukufukuyu?*
    c) Who is going to be involved? *Ndi ndani amene alowe nawo mukafukufukuyu?*
    d) What are the benefits of this study? *Kodi phindu lakafukufuku amaneyu chi chani?*

Reasons for enrolling in the study

8. Why did you enrol in the research? Why did you refuse to enrol in the study? **(Probe: past experience, religion, rumours etc)** *Kodi ndi chifukwa chiyani inu munalowa*

nawo mu kafukufuku ameneyu? Nanga ndi chifukwa chiyani mwakana kulowa mukafukufuku amaneyu?

(Probe: Nanga kumbali ya mbiri yokhudza kafukufuku kudela kuno, nanga chipembedzo, nanga ndalama kapena cholowa mu kafukufuku, Nthawi imene mutenge mu kafukufuku, zomwe munafotokozeredwa zokhudza kafukufuku)

a) How did you make the decision to participate*? Munapanga bwanji chiganizo kuti mutenge nawo mbali mu kafukufuku?*

b) What issues were considered, which of those mattered the most? *Popanga chiganizo, ndi zinthu ziti zimene zinakupangitsani kuti muganize zotenga nawo mbali?*

c) Who did you consult before you made the decision? *Kodi munakambirana ndi ndani zokhudza kafukufuku ameneyu musanapange chiganizo?*

d) Why did you consult them? *Chifukwa chiyani munasankha kuti mukambirane ndi amenewo?*

e) What did they advise you? *Nde anakulangizani chani?*

f) How did other household members feel about your decision? *Kodi anthu ena akunyumba kwanu anaganiza zotani?*

g) How did your friends/ neighbours feel about your decision? *Nanga anzanu analankhula zotani pa chiganizo chomwe munapanga?*

9. What other factors (If not mentioned) would make you enrol or refuse to enrol in a research? (Probe: **Information about study, Length of study, study procedures, rationale of study, incentives**) *Ndi zifukwa ziti zowonjezera pa zimene mwafotokoza kale zimene zingakupangitseni inu kuti mulowe mukafukufuku kapena mukane kulowa mukafukufuku*

(Nanga kumbali ya uthenga omwe waperekedwa okhudza nthawi ya kafukufuku, Chimene mwapemphedwa kuchita mu kafukufuku: kumwa mankhwala, kupereka magazi, kupereka nkodzo, kupereka mamina, zolowa kapena ndalama etc)

Expectations from research

10. What were/ are your expectations from the research? (Probe: personal benefits, public health benefits, feedback findings).
    Kodi inu mukuyembekezera zotani mu kafukufuku ameneyu? *(Probe: Zotsatira za mwanayu, thandizo, kutukula moyo wa anthu)*

Benefits and risks

11. What did you benefit from the research? *Kodi inu munapindulapo chani mu kafukufuku ameneyu?*

12. What were the benefits and risks of the research project? *Kodi ubwino ndi kuyipa wa kafukufuku ameneyu ndi kotani? (Probe: Zotsatira za mwanayu, thandizo, kutukula moyo wa anthu*

13. Do you have any concerns about the research? *Kodi muli ndi nkhawa zina zili zonse zokhudza kafukufuku ameneyu?*
    a) Who did you share your concerns with? Has anyone shared their concerns about this research with you? *Munafotokozera ndani zokhudza nkhawa zanu? Nanga pali anthu ena ali wonse amene anafotokoza nkhawa zawo zokhudza kafukufukuyu kwa ini?*

b) How did they assist you? *Ndiye anakuthandidzani bwanji/ munawathandiza bwanji?*

c) Why did you not share your concerns? *Chifukwa chiyani simunafotokoze nkhawa zanu?*

14. What were some of the difficulties you faced while participating in the study? How were these challenges resolved? were you able to ask questions, seek more clarity or negotiate decisions with the researchers/ field workers? Why? *Munakumanapo ndi mavuto ena onse pamene mumatenga nawo gawo mu kafukufuku? Kodi a kafukufuku anakuthandizani bwanji pa vuto limene mwatchula?*
(Probe: **interaction with FWs, research procedure, context**)

What views do you have with regards to the study team? What views do you have with regard to research?

15. What was your understanding of your role in this research project? *Inuyo mukuwona kuti muli ndi udindo wotani mukafukufukuyu?*

Community participation

16. How do researchers involve community members or research participants in a research? How would you want to be involved in a research project? **(probe: decision making, advice**) *Kodi anthu opangitsa kafukufuku amagwira ntchito bwanji ndi anthu otenga nawo mbali mukafukufuku? Inuyo mungakonde mutamatenga gawo lanji mukafukufuku*

Community Advisory Group

17. Are you aware of any group/ individuals who represent you to researchers? Community Advisory Group members? How were they selected? How does the community work with CAGs

    Kodi inu mukudziwako anthu ena ali onse amene amayimilira anthu a kumudzi ndi a kafukufuku? Anthu amenewa anasankhidwa bwanji? Nanga anthu amenewa amagwira ntchito yanji ku dela kuno?

Future participation in research

18. In future If you are invited to participate in research, would you participate? Why or Why not? What would you consider in making that decision

    Mukazapemphedwa kuti mulowe mu kafukufuku, kodi muzatenga nawo mbali? Chifukwa chani?/ Ndi zifukwa ziti zimene zingakupangitseni kutenga nawo mbali kapena ayi?

End

Appendix 4: Topic guide for FGD

Engage study

FGD topic guide v.2 140815

Section A: Engagement with health services

1. Can you please tell me the names of institutions or NGOs that work in this community?

   Mungandifotokozereko za mabungwe onse amene akugwira ntchito za umoyo kudela kuno?

2. What types of services does each of the provider offer ?

   Mabungwe omwe mwatchulawo, akugwila ntchito yanji?

Section C: Engagement with researchers

Knowledge of health research

3. Can you please tell me what you know about health research?

   Mungandifotokozereko zomwe mumadziwa zokhudza kafukufuku wazaumoyo?

4. Can you please tell me any recent research projects that are currently being done in this community that you are aware of? [Probe: Nature of research, target population]

   Nanga kudela kwanu kuno kukuchitika kafukufuku wanji? Kafukufuku ameneyu akuchitikira kuti ? Nanga akukhudza ndani?

   a. How did you know about these research projects?

   Kodi munadziwa bwanji za kafukufuku ameneyu?

b. What strategies were used to inform communities about research at :

Kodi anthu opangitsa kafukufuku akugwiritsa ntchito njira ziti kuti afotokoze za kafukufuku kwa anthu akumudzi?

[Probe: Hospital, community]

- *Kafukufuku asanayambe*
- *mkatikati mwa kafukufuku*
- *pamathero a kafukufuku*

c. How do people perceive the communication strategies that were being used to inform the community ?

Kodi ubwino ndi kuyipa kwa njira zimene zikugwritsidwa nchito zofotokozera anthu za kafukufu ndi kotani?

d. How do people perceive research procedures such as giving informed consent: written/ oral information about the study, decision making, giving signatures before the procedure, the research procedure itself

Kodi anthu amaziwona bwanji zochitika ku kafukufuku monga: kupasidwa uthenga wa kafukufuku, nthawi imene mumapatsidwa kuti mupange chiganizo, kusayinira pa pepala ndi zochitika mu kafukufuku

e. Who makes decisions on who participates in research in a household? What are the implications If a husband or wife makes a decision without consulting a spouse? Why do we have more women participating in research compared to men?

Kodi ndi ndani amene amapanga ziganizo zokhudza kutenga nawo mbali mu kafukufuku? Nanga chimatika ndi chani ngati amayi kapena abambo apanga

okha chiganizo osafunsana? Ndi chifukwa chiyani amayi ambili amatenga nawo mbali mu kafukufuku kusiyana ndi abambo?

Community participation in research

5. How do researchers work with communities? How is the community involved in research?

   Kodi anthu akudela lino akugwila bwanji ntchito ndi anthu akafukufuku? Nanga anthu a dela lino amatenga mbali yanji mukafukufuku?

   [Probe: gatekeepers/ community members/ community representatives/ community groups/ Who are the field workers/ where do they come from?]

6. What concerns do people have about research? To whom do you report these concerns? How are they addressed?

   Kodi anthu ali ndi nkhawa zotani zokhudza kafukufuku? Nanga nkhawa zimenezi amafotokozera ndani?

   [Probe: gatekeepers/ community members/ community representatives/ community groups/ Who are the field workers/ where do they come from?]

7. What factors make people enrol in research?

   Chifukwa chiyani anthu amalowa mukafukufuku?

8. What factors make people refuse to enrol in a research? what factors make people withdraw from research?

Nanga ndi zifukwa ziti zimene zimapangitsa anthu kuti akane kulowa mukafukufuku?

Nanga ndi chifukwa chiyani anthu amasiya kafukufuku?

Benefits and risks

9. What do people from this community expect from research? How are these expectations met?

   Kodi anthu ku dela kuno mumayembekezera zotani mukafukufuku? Kodi zimenezi zikukwaniritsidwa bwanji ndi a kafukufuku?

   (Link the responses to concerns stated earlier on)

10. How do people look at researchers & research? (What are the perceived risks and benefits of research)?

    Kodi anthu kuno amamulandila bwanji kafukufuku? Kodi ubwino kapena kuyipa kwa kafukufuku ndi kotani?

11. How has research benefited this community? How has it benefited individuals?

    Kodi kafukufuku wathandiza bwanji anthu a dela lino?

    (Link this to concerns mentioned earlier on)

12. What challenges have people experienced due to their involvement in research? How were these challenges resolved?

    Kodi ndi mavuto anji amene anthu olowa mu kafukufuku akukumana nawo? Kodi mavuto amenewa anathetsedwa bwanji?

Community Advisory Group

13. Can you please tell me what you know about Community Advisory Groups?

    Mungandifotokozereko zimene mumadziwa zokhudza ma CAG/ community advisory group?

14. How were they selected? How do you work with CAG members?

    Kodi amenewa adasankhidwa bwanji? Kodi ma membala a CAG akugwira ntchito yanji kudela kuno?

Perception of health services

15. What services are available in your community If one suffers from ill health?

    Kodi munthu akadwala amapita kuti kukapeza thandizo?

    List down on a flip chart

    [Probe: Private, government, traditional healers, religious healers]

16. If someone is ill in your family and you don't go to western medical services, what alternative options are available in your community?

    Ngati simutengela odwala kuchipatala ndi kutinso kwina kumene mungatere odwala?

17. What do you think about the quality of services offered at the places that we have listed down

    Kodi inu mumachiwona bwanji chithandizo chomwe chimaperekedwa kumalo amene mwatchulawo?

    (Personnel: staff attitudes, cost, distance, waiting time, availability of drugs, equipment)

18. What other issues affect your decisions about where to go if someone is sick?

    Nanga ndi zifukwa zati zimene zimakupangitsani inu kusankha malo oti mutengere odwala?

Section B: ***Relevance of current research to participating research communities***

19. Can you please tell me some of the issues that concern you as residents in this community?

    Munganditchulireko zinthu zimene zimakudetsani nkhawa kapena mavuto amene mumakumana nawo ku dela kwanu kuno?

    [Rank the concerns in order of priority from most significant to least significant concerns]

20. Why do these things concern you?

    Chifukwa chani amenewa mukuwawona ngati mavuto?

21. What is currently being done to address some of the concerns that you have raised? Who or which institutions/ individuals are involved in addressing those concerns?

    Kodi mabungwe akuchitapo chani kuti athandize kuthetsa mavuto amene mwatchulawa?

22. What do you think should be done to address these concerns?

    Inuyo mukuwona kuti mavuto amenewa mungathane nawo bwanji?

Appendix 5: Information sheet (English)

Malawi-Liverpool-Wellcome Trust
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A research on community engagement within health research in Malawi

My name is .....and I work for College of Medicine. You are being invited to take part in this research on community engagement. Before you decide to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. You do not have to decide today whether or not you will participate in the research. Before you decide, you can talk to anyone you feel comfortable with about the research. You can also ask questions at any time.

What is Community Engagement in health research?

Community engagement is the involvement of groups of people in planning and carrying out a research. This is done to take into consideration views of people towards the research and protect them from exploitation and abuse. Examples of community engagement initiatives in Malawi include: Community Advisory Group (CAG), community/ health facility meetings and radio.

What is the purpose of this study?

Community engagement is now being promoted in international research. There is a lot of health research taking place in Malawi and institutions such as College of Medicine, Malawi Liverpool Wellcome Trust work with communities through CAGs, Science Cafes, community meetings etc. In this study, we would like to find out the purpose, relevance and benefits of community engagement in

health research. We would also like to observe how researchers work with communities and identify strategies that will improve the ways that researchers work with local people in Malawi. It is our expectation that findings from this study will improve conduct of health research in Malawi.

Who are we asking to participate?

This study will take place within four research projects at Malawi Liverpool Wellcome Trust, Johns Hopkins and Malaria Alert Centre in Chikhwawa and Blantyre districts only. We want to observe and speak to people who are involved in research including: researchers, field workers, CAG members, research participants and other people who have never been involved in research. You are being invited to take part in this study because you live within the geographical areas where the research is taking place or you work for the research projects that we are focussing on.

What will the study involve?

We would like to work alongside staff as they plan community engagement activities and to observe all the community engagement activities that take place in each research project. We would also like to stay in the villages of CAG members for three months in order to observe and participate in their daily activities to understand how they work with communities. Observation will focus on formal community engagement events, and will pay particular attention to physical environment and interactions: in particular, who talks to whom, whose opinions are respected, where participants stand or sit, and non-verbal communication. In addition to spending time with CAG members, we would also like to talk to other people who are involved in research or community engagement activities, to share with us their experiences of taking part in research and how they look at the ways that researchers work with local people. It is anticipated that these conversations will not take longer than two

hours. Our conversation will be recorded and these recordings will be kept safely and used for writing reports.

What are the benefits of this study?

We are asking your help to participate in this study in order to help us improve the ways that researchers involve local people in research. We hope that involving local people in research will help improve understanding of the research and design sustainable projects that will respond to community needs. There are no direct individual benefits to taking part in this study.

Are there any risks to taking part in the study?

We do not feel that there are any major risks if you take part in this study. However, some people may find it challenging and awkward to be observed or have discussions around conduct of research.

Confidentiality

If you decide to participate in the research, your answers to the questions will be recorded and typed. Any information concerning you will be marked with a special study number only, and not your name. All information obtained during the course of this study will be held securely, and stored on paper and computer files. Mrs Deborah Nyirenda will take responsibility of keeping your personal information confidential. We would also like to seek your permission to use quotations from our conversation. We will ensure that anything we use will be carefully selected so that you cannot be identified.

Reimbursements

You will be given a small amount of money If you take part in the research to compensate for your time or transport.

Sharing the Results

The information that you tell us will not be shared with anybody outside the research team, and nothing will be attributed to you by name. There will also be small meetings in the community to discuss the study results and these will be announced. Following the meetings, we will publish the results so that other interested people may learn from the research.

Right to refuse or withdraw

We are asking you to participate voluntarily in this study and there is no obligation at all to do so. We would really appreciate your contributions and opinions and it will be useful for us to hear your views but if you don't wish to participate please tell us at any stage and there will be no consequences or penalties. I will give you an opportunity at the end of the interview to review your remarks, and you can ask to modify or remove portions of those, if you do not agree with my notes or if I did not understand you correctly.

What if I have questions?

If you have any questions about this study, please feel free to ask. If you think of any questions at a later stage, you can contact the following number and speak to Deborah Nyirenda Tel: 01874628/ 01876444 or COMREC Secretariat, College of Medicine, P/Bag 360, Blantyre 3. Tel no. 01989766

Appendix 6: Information sheet (Chichewa)

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<u>Kafukufuku ofuna kudziwa momwe anthu akumudzi akutengera nawo mbali mu mukafukufuku wa zaumoyo</u>

Dzina langa ndine.....ndipo ndimagwira ntchito kusukulu ya kachenjede ya College of Medicine. Mukupemphedwa kuti mutenge nawo mbali mu kafukufuku amene tikufuna kumvetsetsa momwe anthu opangitsa kafukufuku wazaumoyo akugwirira ntchito limodzi ndi anthu akumudzi.Musanaganize zolowa mu kafukufukuyu ndi kofunika kudziwa cholinga cha kafukufukuyu ndi kudziwa chomwe mukuyenera kuchita.Chonde werengani uthenga omwe uli m'munsimu. Tikupatsani mwayi wakuti muganize bwinobwino kapena kuyankhula ndi anthu ena omwe angakuthandizeni kupanga chiganizo. Simukukakamizidwa kuti muganize pompano zolowa mu kafukufuku ameneyu ndipo mukhale omasuka kufunsa mafunso nthawi ina ili yonse.

Kodi tikati 'anthu akumudzi atenge nawo mbali mu kafukufuku wa zaumoyo' zikutanthawuza chani?

'Kutenga nawo mbali mu kafukufuku wa zaumoyo' kumatanthauza njira zomwe zimapereka mwayi kwa anthu a kumudzi kuti adzitenga nawo gawo mu dongosolo la kafukufuku ndi kupereka maganizo awo okhudza kafukufuku. Njira zimenezi zinakhadzikitsidwa ndi cholinga chakuti anthu akumudzi azikhala ndi uthenga okwanira okhudza kafukufuku, maganizo awo azigwiritsidwa ntchito popanga dongosolo la kafukufuku ndi kutinso anthu azitetezedwa ku kafukufuku omwe ali osayenera. Zina

mwa zitsanzo za ndondomeko zomwe zinakhazikitsidwa kuti anthu a kumudzi azitenga nawo gawo mu kafukufuku ndi monga: misonkhano imene imafotokoza za kafukufuku,a mkhala pakati a kafukufuku (CAG) ndi wayilesi.

Kodi cholinga cha kafukufuku ameneyu ndi chani?

Mabungwe ambiri akulimbikitsa kuti anthu akumudzi azitenga nawo gawo mu dongosolo la kafukufuku wazaumoyo. Ku Malawi kuno kuli kafukufuku osiyanasiyana wa zaumoyo. Mabungwe opangitsa kafukufuku wazaumoyo monga Malawi Liverpool Wellcome Trust, College of Medicine ndi ena akutsatira njirazi popangitsa misonkhano yokhudza kafukufuku, ndikusankha anthu oyimira mu CAG. Kafukufuku wathuyu tikufuna kumvetsetsa zolinga za ndondomeko imeneyi ndi ubwino owapatsa mwayi anthu akumudzi kutenga nawo gawo mu kafukufuku wa zaumoyo. Tikufunanso kuwona m'mene anthu opangitsa kafukufuku akugwirira ntchito limodzi ndi anthu akumudzi ndikupeza njira zomwe zingathandize kuti ndondomeko imeneyi ikhale yabwino. Tili ndi chiyembekezo kuti zotsatira za kafukufuku ameneyi zithandizira kuti kafukufuku wa za umoyo aziyenda bwino.

Kodi ndi ndani amene akuyenera kulowa mu kafukufuku ameneyu?

Kafukufuku wathuyu apangidwa ku Chikhwawa ndi Blantyre mu makafukufuku ena amene akupangidwa ndi mabungwe a Malawi Liverpool Wellcome Trust, Johns Hopkins ndi Malaria Alert Centre. Tikufuna kuwona ndi maso m’mene anthu opangitsa kafukufuku amagwirira ntchito ndi anthu akumudzi komanso tizicheza kapena kufunsa mafunso anthu opangitsa kafukufuku, a m'khala pakati (CAG), anthu amene analowa mu kafufuku wa zaumoyo angakhale iwo amene sanalowepo mu kafukufuku. Inuyo mukupemphedwa kutimutenge nawo gawo mu kafukufuku ameneyu chifukwa choti mukukhala ku dela limene kafukufuku wina akuchitika kale kapena kuti mumagwira ntchito ya kafukufuku.

Kodi chizichitika ndi chani mukafukufuku ameneyu?

Ife tikufuna kugwira ntchito ndi opangitsa kafukufuku akamakonza dongosolo lawo ndikuwonerera momwe akugwirira ntchito zothandizira kuti anthu akumudzi atenge nawo gawo mukafukufuku. Komanso tidzikhala ku mudzi kumene kuli a mkhala pakati (CAG) kuti timvetsetse m'mene akugwirira ntchito yawo pothangatira ubale wa opangitsa kafukufuku ndi anthu ena akumudzi. Ife tizikhala tikuyang'ana kapena kuwonesetsa malo omwe akukumana, makhalidwe, machezedwe, akuyankhulana bwanji ndiponso tikufuna kuwona kuti ndi ndani amene akupanga ziganizo. Tili ndi chikhulupililo kuti kukhala nawo kumudzi ndikuwona m'mene zinthu zimachitikira zitithandiza kuphunzira zinthu zambiri zomwe munthu mwina sangafotokoze. Tidzakhalanso tikufunsa anthu mafunso pofuna kudziwa zomwe mumakumana nazo mu kafukufuku wa zaumoyo komanso maganizo anu pokhudza mbali yomwe inu munatengapo mu kafukufuku. Tikuyembeza kuti kucheza kwathu sikuposera ma ola awiri. Zokambirana zathu zizitepedwa ndipo zimenezi zikasungidwa mwachinsinsi kuti tikalembe malipoti.

Kodi kafukufuku ameneyu ali ndi phindu lanji?

Inu mukupemphedwa kuti mutenge nawo mbali mu kafukufuku ameneyu kuti tithandize machitidwe a kafukufuku wa zaumoyo. Ife tikukhulupira kuti kuwapatsa anthu akumudzi mwayi oti atenge nawo gawo padongosolo la kafukufuku kudzathandiza kuti iwo azindikire zolinga za kafukufuku ndipo kuti kafukufuku azikhala othandiza kutukula umoyo wa anthu. Palibenso phindu lina lomwe mungapeze polowa mukafukufuku ameneyu.

Kodi pali chiopsezo chanji ndikalowa kafukufuku ameneyu?

Ife sitikuwonapo chiopsezo china chili chonse, komano anthu ena atha kukhala omangika kuti afotokoze momwe kafukufuku akuchitikira kapena kuti tiziwonerera zimene akuchita.

Chinsinsi

Inu mukapanga chisankho kuti mulowe nawo mu kafukufuku ameneyu, zokambirana zathu tizazitepa, ndikuzilemba. Zotepazo kapena zolembazo zidzakhala ndi nambala yapadera osati dzina lanu.China chili chonse chokhudza kafukufuku ameneyu chidzasungidwa mwachinsinsi ndipo Mrs Deborah Nyirenda ali ndi udindo owonesetsa kuti china chili chonse chasungidwa mwa chinsinsi. Ife tikupempha kuti tikathe kugwiritsa ntchito zina mwa zinthu zomwe mutafotokoze koma tikawonesetsa kuti dzina lanu lisatchulidwe.

Malipilo

Inu mudzapatsidwa ndalama pang'ono chifukwa chotenga nthawi yanu mukafukufuku ameneyu.

Zotsatira za kafukufuku

Zonse zimene tikambirane sizikawululidwa kwa anthu ena amene asakupanga nawo kafukufuku ameneyu ndipo dzina lanunso silizatchulidwa. Ife tidzakuyitanani ku msonkhano kuti muzamvere zotsatira za kafukufuku ameneyu. Kenako ife tikalemba malipoti kuti anthu ena akadziwe nawo zomwe tapeza mu kafukufuku ameneyu.

Ufulu okana kapena kulowa nawo mukafukufuku

Inu mukupemphedwa kulowa mu kafukufuku ameneyu mosakakamizidwa ndi munthu. Ifeyo tikufuna kumva maganizo anu koma ngati simukufuna kulowa mu kafukufuku ameneyu chonde tidziwitseni nthawi ina ili yonse. Inu mukakana kulowa mu kafufuku ameneyu simudzayimbidwa mlandu wina uli wonse ndi opangitsa kafukufuku. Pamapeto pazokambirana zathu, ndifotokoza

zonse zimene takambirana ndipo inu muli ndi ufulu kutsutsa kapena kuwonjezera zimene sindinamvetse bwino.

Ndingatani nditakhala ndi mafunso ena?

Ngati muli ndi mafunso okhudza kafukufuku ameneyu, chonde khalani omasuka kufunsa. Ngati mungakhale ndi mafunso owonjezera muyimbe foni ndikulankhula ndi Deborah Nyirenda Tel: 01874628/01876444 or COMREC Secretariat, College of Medicine, P/Bag 360, Blantyre 3. Tel no. 01989766

Appendix 7: Informed consent form for SSI and FGD (English)

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www.mlw.mw

<u>An investigation of community engagement within medical research in Malawi</u>

1. I have received and read the information sheet provided by the researcher that explains in detail the reasons for the study.
2. I have read, discussed and understood the purpose of the research.
3. I have asked all the questions that I have about the purpose of the research and feel happy that I have enough information about it.
4. I understand the reasons for this interview and I am willing and happy to complete it.
5. If I agree to take part in the interview I understand what I have to do.
6. I know that I have the right to refuse to answer any questions
7. If I do not agree to take part in the interview I understand that I will not be penalised for doing so by the researcher nor by any other member of the study team.

I voluntarily agree to take part in the interview.

----------	-----/--------/-------	----------
Name of participant (BLOCK CAPITALS) print	Date	Signature or thumb

----------	-----/--------/--------	----------
Name of Study Team Member	Date	Signature or thumbprint

Appendix 8: Informed consent for SSI and FGD (Chichewa)

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<u>Kafukufuku ofuna kudziwa momwe anthu akumudzi akutenga nawo mbali mu mukafukufuku wa zaumoyo</u>

1. Ndalandira komanso kuwerenga tsamba la uthenga limene laperekedwa ndi opangitsa kafukufuku limene likufotokozera mwatsatane-tsatane cholinga cha kafukufukuyu.
2. Ndawerenga, kukambirana komanso kumvesetsa cholinga cha kafukufuku.
3. Ndafunsa mafunso onse amene ndili nawo okhudzana ndi cholinga cha kafukufuku ndipo ndine okondwa pokhala ndi uthenga okwanira okhudzana ndi kafukufukuyu.
4. Ndikumvesetsa cholinga cha kafukufuku ndipo ndili okonzeka komanso okondwa kusayinila tsambali.
5. Ngati ndavomereza kumalizitsa kusayinila tsamba la mafunsoli, ndikumvesetsa chimene ndikuyenera kuchita.
6. Ndikudziwa kuti ndili ndi ufulu okana kuyankha mafunso ena aliwonse.
7. Ngati sindivomera kutenga nawo mbali mu kafukufuku ameneyu, ndikumvesetsa kunena kuti sindidzayimbidwa mlandu pochita zimenezo ndi opangitsa kafukufuku kapena membala wina aliyense wa gulu la kafukufuku.

Ndikuvomereza mosakakamizidwa kusayinila tsamba la mafunso.

---------- -----/--------/------- ----------

Dzina la otenga nawo mbali Deti Siginichala kapena chidindo
(ZILEMBA ZAZIKULU)

---------- -----/-------/--------- ----------

Dzina la membala wa kafukufuku Deti Siginichala kapena chidindo
(ZILEMBA ZAZIKULU)

Appendix 9: Informed consent form for observations (English)

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<u>An investigation of community engagement within medical research in Malawi</u>

1. I have received and read the information sheet provided by the researcher that explains in detail the reasons for the study.
2. I have read, discussed and understood the purpose of the research.
3. I have asked all the questions that I have about the purpose of the research and feel happy that I have enough information about it.
4. I understand the reasons for the observations and I am willing and happy to take part.
5. If I agree to take part in the study, I understand what I have to do.
6. I know that I have the right to refuse to answer any questions
7. If I do not agree to take part in the study I understand that I will not be penalised for doing so by the researcher nor by any other member of the study team.

I voluntarily agree to take part in the study.

---------- -----/--------/------- ----------

Name of participant Date Signature or thumb print
(BLOCK CAPITALS)

---------- -----/--------/-------- ----------

Name of study team member Date Signature or thumbprint
(BLOCK CAPITALS)

Appendix 10: Informed consent form for observations (Chichewa)

Malawi-Liverpool-Wellcome Trust
Clinical Research Programme
PO Box 30096
Chichiri
Blantyre 3, Malawi
Tel +265 1876 444
Fax +265 1875 774
www.mlw.mw

<u>Kafukufuku ofuna kudziwa momwe anthu akumudzi akutenga nawo mbali mu mukafukufuku wa zaumoyo</u>

1. Ndalandira komanso kuwerenga tsamba la uthenga limene laperekedwa ndi opangitsa kafukufuku limene likufotokozera mwatsatane-tsatane cholinga cha kafukufukuyu.
2. Ndawerenga, kukambirana komanso kumvesetsa cholinga cha kafukufuku.
3. Ndafunsa mafunso onse amene ndili nawo okhudzana ndi cholinga cha kafukufuku ndipo ndine okondwa pokhala ndi uthenga okwanira okhudzana ndi kafukufukuyu.
4. Ndikumvesetsa cholinga cha kafukufuku ndipo ndiri okonzeka komanso okondwa kusayinila tsambali.
5. Ngati ndavomereza kumalizitsa kusayinila tsamba la mafunsoli, ndikumvesetsa chimene ndikuyenera kuchita.
6. Ndikudziwa kuti ndili ndi ufulu okana kuyankha mafunso ena aliwonse.
7. Ngati sindivomera kutenga nawo mbali mu kafukufuku ameneyu, ndikumvesetsa kunena kuti sitidzaimbidwa mlandu pochita zimenezo ndi opangitsa kafukufuku kapena membala wina aliyense wa gulu la kafukufuku.

Ndikuvomereza mosakakamizidwa kusayinila tsamba la mafunso.

---------- -----/--------/------- ----------

Dzina la otenga nawo mbali Deti Siginichala kapena chidindo
(ZILEMBA ZAZIKULU)

---------- -----/-------/-------- ----------

Dzina la membala wa kafukufuku Deti Siginichala kapena chidindo

Appendix 11: Coding framework

Name	Sources	References	Created On	Created By
Benefits of research	28	160	10/12/2015 3:50 PM	DN
Blood	17	55	7/24/2015 11:23 AM	DN
Communication	19	111	10/7/2015 9:33 AM	DN
Letters	6	26	10/7/2015 9:33 AM	DN
Community concerns	19	127	10/12/2015 11:13 AM	DN
prioritisation of concerns	6	15	10/12/2015 11:20 AM	DN
Expectations	22	60	10/12/2015 8:17 AM	DN
treatment of research participants	17	17	10/12/2015 8:23 AM	DN
exposure to research	23	109	7/24/2015 11:17 AM	DN
coercision	14	14	12/11/2015 9:04 AM	DN
entomology	13	45	6/7/2016 9:10 AM	DN
home visitation	10	42	10/6/2015 4:16 PM	DN
stickers-numeration	3	19	10/6/2016 11:03 AM	DN
House improvement	12	80	6/7/2016 9:12 AM	DN
LSM	10	67	10/5/2016 3:41 PM	DN
malaria test	11	44	6/7/2016 9:10 AM	DN
Mosquito nets	11	51	10/5/2016 3:32 PM	DN
Negative experience	15	18	10/6/2015 4:06 PM	DN
Positive experience	1	1	10/6/2015 4:06 PM	DN
Fear worries	22	88	10/8/2015 9:34 AM	DN
gender issues in research	9	36	10/13/2015 7:44 AM	DN
Health interventions	14	170	10/12/2015 11:02 AM	DN
Africa parks	3	39	10/10/2016 2:47 PM	DN
CADECOM	1	2	10/17/2016 5:34 AM	DN
CBO	1	5	10/20/2016 5:21 AM	DN
Concern universal	4	8	10/17/2016 5:34 AM	DN
COWVOC	1	2	10/17/2016 5:44 AM	DN
Eagles	1	3	10/21/2016 5:10 AM	DN
HIV & matters	1	1	10/14/2016 1:52 PM	DN
Hunger project	6	9	10/10/2016 2:47 PM	DN
Kapichira	1	3	10/19/2016 4:52 AM	DN
MMP	5	17	10/14/2016 1:50 PM	DN
mtukula pakhomo	1	12	10/10/2016 4:02 PM	DN

SWAM	4	15	10/17/2016 5:45 AM	DN
Ubale	4	16	10/14/2016 1:53 PM	DN
Wala	1	1	10/21/2016 5:13 AM	DN
water for people	2	3	10/10/2016 3:06 PM	DN
WFP	1	2	10/17/2016 5:41 AM	DN
World vision	1	3	10/14/2016 1:54 PM	DN
Health services facilities	14	39	10/12/2015 11:05 AM	DN
quality of services	7	22	10/12/2015 11:09 AM	DN
Illness experience	4	10	11/5/2015 2:41 PM	DN
interactions with people	25	103	7/24/2015 11:20 AM	DN
Family	5	9	10/7/2015 10:13 AM	DN
researchers	14	42	12/17/2015 10:29 AM	DN
village heads	2	4	10/25/2016 3:32 PM	DN
Length of study	4	8	7/24/2015 11:22 AM	DN
Participation collaboration	23	68	10/7/2015 4:34 PM	DN
Animators	9	20	6/7/2016 4:39 PM	DN
balancing roles	2	10	10/25/2016 5:32 PM	DN
Motivation	2	2	10/25/2016 2:28 PM	DN
selection	3	5	10/25/2016 2:07 PM	DN
CAG motivation	3	3	1/4/2016 4:07 PM	DN
CAG residence	2	6	1/4/2016 10:32 AM	DN
CAG roles	4	26	1/4/2016 10:28 AM	DN
CAG selection-CM selection	5	16	1/4/2016 2:09 PM	DN
commitees	11	61	6/7/2016 4:45 PM	DN
community representatives	7	16	10/12/2015 2:09 PM	DN
representation	3	14	1/4/2016 2:07 PM	DN
social relationships	1	1	10/25/2016 3:29 PM	DN
Placenta	1	4	12/14/2015 9:45 AM	DN
Power	13	24	10/7/2015 10:32 AM	DN
Processes CE	1	1	4/5/2016 1:44 PM	DN
expertise	1	1	4/5/2016 1:56 PM	DN
feedback	1	7	4/5/2016 1:46 PM	DN
role to engage	1	1	4/5/2016 1:56 PM	DN
rationale CE	0	0	4/4/2016 3:38 PM	DN
acceptability	4	5	4/4/2016 3:44 PM	DN
improves quality of research	4	5	4/4/2016 4:02 PM	DN
inform	4	5	4/4/2016 3:41 PM	DN
local knowledge	2	2	4/5/2016 4:07 PM	DN
promote sharing facts not rumours	3	4	4/4/2016 3:51 PM	DN
recruitment	4	6	4/4/2016 4:57 PM	DN
reduce fear	3	4	4/4/2016 3:46 PM	DN

respecting norms	1	1	4/4/2016 5:01 PM	DN
support guidance	1	6	4/4/2016 4:58 PM	DN
Results	19	75	10/7/2015 10:10 AM	DN
study results	6	27	10/7/2015 10:11 AM	DN
test results	8	11	10/7/2015 10:11 AM	DN
sensitization meetings	8	25	4/5/2016 8:19 AM	DN
attendance and participation	10	55	4/5/2016 9:37 AM	DN
community reception	1	17	4/5/2016 8:40 AM	DN
Drama	1	3	4/5/2016 8:50 AM	DN
group dynamics	1	1	4/5/2016 8:20 AM	DN
Group understanding	2	10	4/5/2016 8:22 AM	DN
inaccurate representation of facts	1	2	4/5/2016 8:24 AM	DN
Invitation approaches	1	1	10/25/2016 2:18 PM	DN
managing large groups	1	3	4/5/2016 8:45 AM	DN
Understanding of research	34	290	7/24/2015 11:19 AM	DN
local understanding of illness	10	42	6/10/2016 8:49 AM	DN
motivation to enrol	18	55	10/7/2015 4:19 PM	DN
reasons for refusal	14	30	10/12/2015 2:40 PM	DN
Understanding of specific study	20	60	10/7/2015 9:57 AM	DN

Appendix 12: Coded transcripts

<Internals\\Case study 1\\FGD\\Eng_FGD8_SL_061115> - § 1 reference coded [2.36% Coverage]

Reference 1 - 2.36% Coverage

Interviewer: uh huh. Chabwino. Enafe amene sitinatengepo mbali mukafukufuku pali chifukwa chimene sitinatengepo mbari mukafukufuku kaya wa ku queens

02: Nthawi ina yake imene amabadwa mwana wanga woyamba kunali kafukufuku kaya amati wa matenda a ntchetcha kaya ndi polio ndayiwala matenda ake koma ndimangokumbukira ndiye amapempha azimayi amene ali womasuka kuti akalowe nao mukafukufuku kuti akalowe nao m'mene muja, ndiye ena amapita ena amakana kumanena kuti mzoipa zimenezo akatenga mwana wanu akalowa m'menemo azifuna azimutenga magazi pafupi pafupi azimubaya azimupanga panga chani chani kukhala ngati kuwapanga discourage amzao amene amafuna kutani kulowa ndiye inenso ndinali gulu lomwelo lomaopa kuti ngati awa akunena I think anazionapo ndiye kuti mwanayi nthawi zonse azikhala akumuyendera kapena kumuyitanitsa azamubaye azamutenge magazi chani ndikanatha kulowa koma ndinalephera kulowa mukafukufuku ameneyo chifukwa chachimenecho.

<Internals\\Case study 1\\FGD\\FGD1_ND_110815_SM_Chi> - § 7 references coded [9.62% Coverage]

Reference 1 - 1.21% Coverage

Interviewer: Chabwino nanga tiyeni tiyambe kuona zifukwa zimene anthu amakanira kulowa nawo mukafukufuku. Ndi chifukwa chani anthu amakana kutenga nawo mbali mukafukufuku kapena kulowa mukafukufuku?

PF: Kumakhala kuopsezana azimayi, iiiiiiih mukafukufuku mwalowayo, mwanayotu akangotere sakula wapita ameneyo azingodwaladwala. Komanso amapereka magazi ambirimbiri ndiye azimayi amachita mantha chifukwa akundiuza ngati ineyo munthu okuti sindikudzidziwa ndiye kuti ndichita mantha sindilowa; mwana wangayu akamtenge magazi ambirimbiri, iiiiiih mwana wangayu amwalire ayi sizoona timatero chifukwa choopsezana.

Reference 2 - 1.62% Coverage

Interviewer: Munakambaponso kuti anthu amakhala akuopa kutenga nawo mbali pa kafukufuku chifukwa chokuti akafukufuku amatenga nawo magazi eti. Pali chiopsezo china chilichonse kapena zinthu zomwe anthu amakhala akukamba kunoko zokhudzana kutenga magazi? Anthu amachita mantha ndi chani?

PF: Anthuwo mantha inde amangopanga koma sitinamvepo kuti amene analowa mukafukufuku kuti mwana uja wachitika kapena zachitika sinnamvekoyi. Ndimangomva kuti iiiih anditenga mwana wanga magazi.

PF: Komanso chomwe ndikuganiza kukafukufuku kumbali ya anaku kuti mwezi uno kamtenge magazi, mwezi wamawa antenge magazi nkana anthu amachuluka zofotokoza kuti iiiiih abale monse mwana anayambira kumtenga magazi muja, magazi akumapita nawo kutiko eyetu.

Reference 3 - 1.61% Coverage

Interviewer: Chabwino koma muzokamba za anthu amanena kuti magaziwo amapita kuti?

PF: Aaah ifeyo ifeyo palibei chomwe tikudziwa komano timangomva anthu akamakamba kuti eeeh mwana wanuyi ngati ndiye akumtenga magazi ndiye kuti basi geni ya anthu ena ake imeneyo. Olo ukapita kuchipatala konkuja umva iiih mwana wanga angomutenga magazi daily ndiye ukafunsa kuti samakuwuzani zotsatira umva sinnamvekoyi. Koma ine ndimaona kuti tsiku lomwe anantenga magazilo amafuna ayeze mthenda ina yake ndiye akhala kuti wapitanso sinanga kumene kuja umapita nthawi zambiri ukakhala kuti wadwala eti; ndiye ukapitanso mwina amafunanso kuti ayezenso mwina nthenda ina aone kuti ngati ichichi chinakanika mwanayu akupitilizabe kudwala timtengenso magazi mwina tiimuyezenso nthenda iyiyi.

Reference 4 - 0.28% Coverage

PF**:** Komanso timafuna kuti mwina akatenga ngati magazi aja eti, umafuna kuti zotsatira zija umve pompopompo, ndi zomwe amafuna ndiikhulupilira.

Reference 5 - 0.83% Coverage

Interviewer: Nanga mwina ziopsezo zina zomwe anthu amaopsezana kunoko zokhudza kafukufuku kupatula zomwe mwandifotokozera kale ndi monga chani ndi chani?

PF: Monga ukakhala kuti watengetsa magazi, magazi amene aja akufuna akagwiritse ntchito, akagulitse eeeeh akatani ngati zomwezo zikunenedwazo.

Interviewer: Ndiye amati akagulitse kutiko?

PF: Akagwilitse ntchito ina pamenepopo inuyo mwangoluza magazi anu kupereka.

Reference 6 - 1.95% Coverage

Interviewer: Chifukwa ndikufuna ndimvetsetse kwambiri ngati kumbali yamagaziyo chifukwa ndakhala ndikucheza ndi anthu osiyianasiyana ndiye

zikumaoneka kuti ambiri akumalankhula nkhani yokhudza kuperekela magazi. ndimafuna kuti ndimvetsetse kuti kodi anthu nkhawa yawo imakhala pati kuti magaziwo akagwiritsidwa ntchito motani, anthu akunoko amati magaziwo amakagwiritsidwa ntchito bwanji?

PF: Amati asatanic, mumva iiiih inu mwalora kutengetsa magazi zimenezo zimakhala zovutatu.

PF: Koma kungoti masiku anowa a Malawi anataya chikhulupiliro mwamadokotala awo chifukwa cha zomwe zimachitika kwambiri ku chipatala timatengedwa ngati kuti ifeyo penapake zinthu zomwe timapangidwa kuchipatalako sizimene umayembekezera kuti ukakumane nazo ndiye mapeto ake tikachoka kumene uja timatenga nkhani kumenekuja ndikumabweretsano kumudzi ngati kuno; kuchipatala andipanga zakutizakuti ndiye kuti pamene paja timakhala kuti nkhani ija tikungotani tikungogawana gawana wina amuwuza mzake.

Reference 7 - 2.12% Coverage

PF: Olo nkhani zolera zomwezi ndithu mwabayitsa jackson'mu amuna anu ine apa basitu mudzingokhala basi mwangokumana akazi okhaokha apapa palibepo china chilichonse chomwe chizichitika.

Timakambirana tikakhala m'magulu chonchi iiiiiiih munakabayitsa nkanatu amuna anu aja akumapangatu chakutichakuti. Kumangokhala kuopsezana basi ndiye timati tikangoyinyamula nkhani kuchipatala kuti mwakuti mwakuti olo dokotala wakupanga chinthu china chake choyipa ukadzangomuwuza mzako m'modzi basi ndiye kuti nkhani imene ija yapita.

Ndi m'mene zimakhaliratu nkhani ngati zakafukufukuzi kuti mwina unapita ku kafukufuku wina wake ndiye akupangako chinthu china chake kaya akutenga lero magazi, mawa akutenga magazi masiku enawo umatha kumangodziyang'anira komano akadzakutenga ka chi four ko umadzawauza kuti iiiiiih amwali iiiiih bodza kukafukufuku ndikumangopita kuja akumangonditenga magazi sindidzapitakonso. Iiiiiih magazi aja akumapita nawo ku satanic ku satanic, mwaona zinthu ngati zimenezo ndiye masiku ano anthu tikumakhala ndi zikhulupiliro kwambiri eyetu.[1]

<Internals\\Case study 1\\FGD\\FGD2_ND_140815_SM_Chi> - § 1 reference coded [0.51% Coverage]

Reference 1 - 0.51% Coverage

PM: Kusadziwa, Chikayiko, kusadziwa chomwe kafukufukuyu pakutha pake atapindule. Chachiwiri mantha amabwera ngati ikakhala nkhani yopeleka magazi, anthu amaganiza kuti iiih ndiye akandiyeze HIV/ Aids, akadziwe kuti

ineyo ndikudwala, nthawi zina ukawapatsa information ya dzina ndi dzina mwina umati ndi zina langa so mkhani yaikulu ndikusadziwa kuti kafukufukuyo kwenikweni akufuna kupindula chani; ndi zomwe zimapangitsa anthu kuti asapange participate.

<Internals\\Case study 1\\FGD\\FGD3_ND210815_SM_Chi> - § 8 references coded [6.40% Coverage]

Reference 1 - 0.80% Coverage

PF: Vuto lina ndikuyankhula kwa anthu ena eti, munthu ali kunyumba mwina akudwala ali ndi vuto ndiye ndingoyelekeza m'mene mwana wanga ankadwala ndiye ndinamuwuza tiye ku Malaria project ukalowe kafukufuku azimzake anamuwuza kuti usakalowe amatenga magazi ambiri ukamwalira. Pamenepo samam'thandiza anafikana poti mwana uja anadwalika ndithu ndinachita kubereka kumbuyo popeza ine ndinaziwa ubwino wakafukufuku ndinamulimbikitsa kuti akunama samatenga magazi ambiri amangotenga pang'ono. Ndinamtenga kubwera naye pa hall pa anamthandiza panopa ali bwinobwino panopa akukayamba ntchito. Koma chifukwa choti iyeyo ankangozimva ali kunyumba. Vuto la ife ndi loti anthu timangogwetsana mphwayi tisanawone kuti sizabwinoyi akakutenga magazi mabotolo 4 ukafera pompo. Ndiye ndimaona ngati limenelonso ndi vuto la anthu pakhomo.[2]

Reference 2 - 0.86% Coverage

Interviewer: Nanga ndi chifukwa chani anthu amaopa kupereka magazi?

PF: Anthu amakana kupereka magazi amaopa kuti mwina ineyo akandipeza ndi HIV ndiye ndikakapezeka ndi HIV ndiye mwina sindinakonzekere, nkhawa mwina adzikhala odandaula komanso amati mwina dziko lonse ladziwa ndinkana amakana kupereka magazi.

Interviewer: A number 6.

PF6: Ndimafunanso ndiyankhe funso lomwelo chifukwa ambiri tikumatha kukana kuti iiiiiiih akandiyeza magazi ndiye kuti akakakandipeza ndili positive ndiye kuti dziko lonse limva koma kumakhala kusadzidikirayi. Koma ndi bwino kuti ndipite ndikamve chomwe andiyitanira ndikayezetse ndimve zotsatira zanga inenso ndidziwawuza amzanga m'maderamu.

Reference 3 - 0.38% Coverage

PM: Nanga kukakhala kuyezetsa kosagwilitsa ntchito magazi zimakhala bwanji?

PF: Kuyezetsa kosagwilitsa ntchito magazi ndi zinthu zoti zimatengera ndi m'mene anabwera ndika stick kawo kunena kuti akukuyeza mkamwa eti, komano anthube ndi ochepa amene amachilandira chimakula ku anthufe ndi

mantha kuti mwina akandiwuza kuti ndili nako ndi chimene chimapangitsa kuti munthu usayezetse magazi.

Reference 4 - 1.50% Coverage

Interviewer: Ndiye kumbuyoku mwakhala mukundifotokozera zina ndi zina mwa nkhawa zomwe mumakhala nazo zokhudza kafukufuku ndiye ndimakuwuzani zoti ndifunsabe bwino pambuyo pano. Panopa ndimafuna mundifotokozere nkhawa zomwe anthu amakhala nazo zokhudza kafukufuku. Panakambidwa nkhani ya nsengwa, panakambidwa kaya nkhani ya magazi ndiye panopa ndimafuna kuti timasukilane; anthu amakhala ndi nkhawa zanji chifukwa munafotokoza iyayi anthu samvetsetsa kaya chani. Ndi nkhawa zanji zomwe anthu amakhala nazo zokhudza kafukufuku.

PF2: Ambili amakhala ndi nkhawa zamagazi eti. Ambili amanena kuti iiiih amatenga magazi ambiri, amatenga botolo lonse ndiye iiiih ayi ife sitidzipita kumeneko komano ena akakhala kuti ali mukafukufuku muja amatha kuwafotokozera kuti iyayi satenga magazi ambili amangotenga pachala pang'ono kuti akumveni kuti nthupi mwanu mulibwanji. Ndiye ambiri amaopa ziti; ambiri amaopa zimenezo koma amakhala akuwalimbikitsa kuti sapanga choncho.

Interviewer: Okay nkhawa zina zomwe anthu akudera kwanu amakhala nazo zokhuza kafukufuku?

PF7: Nkhawa yambiri yomwe imakhala ndi anthu amanena kuti munthu ukalowa mukafukufuku ndiye kuti mwezi ulionse udzikapeleka magazi ndiye amaopsezedwano kuti nanga munthu adzingotenga magazi mbotolo ndiye zimapezeka kuti magazi akuthera komanso munthu ukakhala kunena kuti sukupitako amakutsatira mpakana pakhomo ndiye anthu aja amakhala ndi mantha kuti nanga ndizitengetsa magazi nthawi ndi nthawi zimapezeka kuti magazi anga atha ndi nkana anthu amakana kuti alowe nawo mukafukufuku.

Reference 5 - 1.18% Coverage

Interviewer: komano tikufuna tidziwenso kuyipa kwa kafukufuku anthu amati kuyipa kwa kakafukufuku ndi chani; kusamvetsetsa komwe amanenako ndiye mundifotokozere kuti samamvetsetsa chani?

PF7: Koyamba sitimamvetsetsa chifukwa chonena kuti anthufe timakamba kuti mukafukufuku amafuna kutenga magazi azikawagulitsa ndiye ndi nkana munthu samakhala ndi chidwi choti akalowe mukafukufuku komanso umakhala ndi mantha kuti munthu ukatengedwa magazi ndi zoti adzikutsatira kunena kuti magazi akowo adzigwiritsa ntchito komanso magazi akowo ndiye kuti ukalowa kafukufuku ndi munthu oti ali ndi kachilombo chifukwa

chakusamvetsetsa kwa anthu komano chifukwa chonena kuti anthu akafukufuku akumatifikilabe m'maderamo ngakhale m'midzi ndiye anthufe chifukwa choti akutifikira tikumachimvetsetsa chifukwa loko ineyo m'mene ndikunena kuti mphwangayo siwakunokoyi anachokera ku Lirangwe atampanga akafukufuku anafika ndi mwana kuja ku surgical ku Queens kuja anabweranso akafukufuku kungotenga magazi, anamuwuza kuti umakhala kuti;

Reference 6 - 0.41% Coverage

Interviewer: Inu mumakamba kuti kafukufuku amati ndi wasatanic, chifukwa chani ankanena kuti kafukufukuyo ndiwasatanic?

PF: Akuti chifukwa choti ineyo ndinalowa mukafukufuku ndipo mukafukufukuyo amatenga magazi olo atenge magazi ochepa magazi aja amapeza nawo ndalama amapita nawo ku South Africa kukagulitsa ndiye amapeza ndalama zambiri. Ndiye amatenga ndalama zimenezija kumatipatsa ifeyo.Ndiye akuti ineyo ndi wasatanic[3]

Reference 7 - 0.91% Coverage

Interviewer: Kuwonjezera apo ndi mavuto anji amene anthu amakumana nawo chifukwa chotenga nawo mbali mukafukufuku anafotokozapo kale tingowonjezera pamenepo ndi mavuto anji amene ifeyo tikuwadziwa kuti akutiakuti analowa mukafukufuku anakumana ndi vuto lakuti lakuti?

PF: Ineyo vuto limenelolo koma panopa umboni ndilibe koma anzangawo amene ankanena zimenezo zomukaniza mwana wangayo eti ndi amene anandiuza kuti kafukufuku ndi oyipa, iwowo analowa kafukufuku akuti oyeza mikozo mpakana mwana wawo anamwalira chifukwa chosowa magazi.

Interviewer: Chinachitika ndi chani kuti mwana wawo akamwalire?

PF: Basino ankakamba nkhani zake zamagazi zomwezo kuti ankangowapatsa koyezera. Tingoyelekeza lero 21, ndiye kuti ngati lero apita akawatenga magazi mwezi wina ujanso akawatenga magazi nkupezeka kuti mwana ndikumwalira. Ndipamene ankanena kuti kafukufuku ndi oyipa mwana wanga anamwalira chifukwa chomakantenga magazi pafupipafupi.

Reference 8 - 0.36% Coverage

Interviewer: Okay.

PF: Inenso ndikuvomerezana ndi mfundo yomwe anena awo kuti ambiri amatuluka mukafukufuku chifukwa chokuti akangoti apeza vuto loti mwina mwana wawo wamwalira amati ndiye kuti vuto ndikumtenga magazi kuja

chifukwa mwanayo alibe kale ndiye akumukakamiza kuti amutenge magazi basi ndalisiya ndiye vuto lomwe ndimaona ngati limakula ndilimenelo.

<Internals\\Case study 1\\FGD\\FGD4_ND210815_SM_Chi> - § 5 references coded [3.37% Coverage]

Reference 1 - 1.11% Coverage

Interviewer: Okay mukafukufuku ameneyo chikumachitika ndi chani pamene mwandifotokozera mukunena kuti akufuna ana osapyola zaka 5, kwenikweni chomwe akumachita nawo ana a zaka 5'wo akupanga nawo chani

PM: Ali pa mfundo yomweyo mwafotokoza kuti akuvuta ndi azibambo kuti mwana wanga usapite naye uku, ndi chifukwa chani azibambo akuvuta?

PM: Azibambo ambiri kumakhala kusamvetsetsa uthenga uja. Amati pamene tikulengezetsa zakafukufuku uja, amati amene akulengezetsa zakafukufuku uja amalandira ndalama kuchokera ku boma ndi cholinga choti mwina ana athu aja akatengedwe magazi. Magazi amanenewo akawagulitse aboma boma lipezepo benefit yawo. Ndiye ife timakhala kuti tikulengezetsa zimene zijazo ndi anthu wamba ndiye amakana zinthu ngati zimenezijazo kuti ana athu asapite kumene kujako chifukwa choti achipatala akatenga ana athu magazi.

Reference 2 - 0.88% Coverage

Interviewer: chabwino tipitilire, ndimafuna kudziwa kuti anthu a dela linolo akugwira bwanji ntchito ndi anthu opangitsa kafukufuku, olo tifunse kuti anthu a dela linolo akutenga gawo lanji pa kafukufuku?

PM5: poyamba anthu a dela linolo amavuta, anali anthu osamvesetsa koma pano amamvesetsa, chifukwa pakanakhala ngati m'mene amavutira m'buyomu poyamba paja nkhani ya kafukufukuyi bwenzi kulibe.

Interviewer: kodi kumbali ya kafukufuku amavuta chani?

PM5: Amavuta chifukwa cha zochitika, amavuta kunkhani yotenga magazi amati, iwo akufuna kutenga magazi a mwana wanga kuti chani, ndiye amathawitsa mwana uja.

Interviewer: Mmmhu

Reference 3 - 0.44% Coverage

PM5: kapena ngati ana aja amawatenga magazi kusukulu, ana aja kusukulu samapitako

Interviewer: Mmmm

PM5: Ndiye nthawi inoyo ndikukhulupilira kuti, pang'ono-pang'ono, kudzera kuphunzitsidwa, anthu tsono ayamba kuyera m'maso, akuzindikira chimene boma likufuna, kapena a chipatala chimene akufuna, amathandiza kwambiri a chipatala.[4]

Reference 4 - 0.77% Coverage

Interviewer: Kodi anthu akuno, ali ndi nkhawa zotani pa kafukufuku ?

PM6: Nkhawa zimene amakhala nazo ndi zimene zafotokozedwa kale, kuti, akafotokozeredwa kunena kuti tibwere ndi kafukufuku wotenga magazi , ndiyeno akukatenga magazi, anthu aja, m'malo moti akanafotokoza choona cheni-cheni, amakhala kuti akuonjezera kunena kuti, ukapitako kumeneko akakutenga magazi, ndiyeno anthu amaopsyezedwa ku nkhani ngati zimenezo, chimodzi-modzinso aja amatenga za mamina aja, anthu amaopsyezedwa kuti akamutenga mamina-akamutenga mamina, ndiye mwana wangayu akhala bwino? Ndizimene zimaopsya,

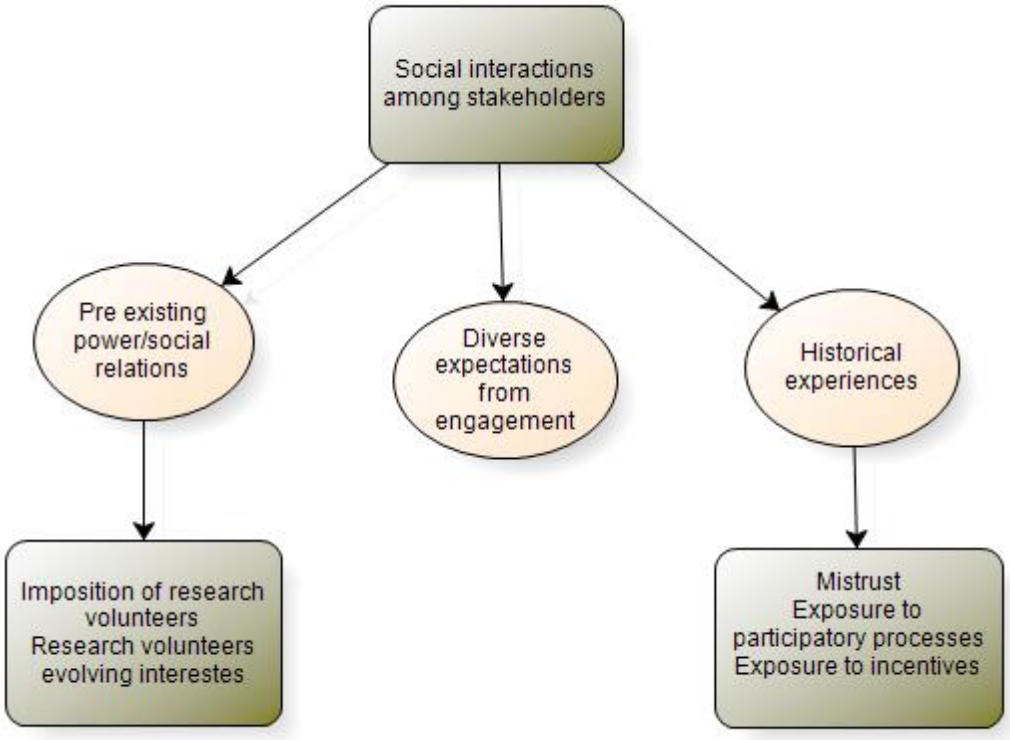
Reference 5 - 0.18% Coverage

Interviewer: Mmmhu.

PM6: Mapeto ake ena amaopa kuti alowe nawo mukafukufuku chifukwa cha kuopsyezedwa ndi zimenezo.

Interviewer: Okay.

Appendix 13: Model used to explore connections across themes presented in chapter 5



Appendix 14: An example of a framework matrix used to compare research participants views

	General Understanding of research	Understanding of specific study	Motivations to enrol in the study	Expectations from the research
Participant 1, HHI **(Female, 35yrs, no education)**	*Don't know meaning of research*	*Measuring/testing the nose to find the 13 germs.* *There is a disease that starts from the nose and it is contagious*	*Was told it is a vaccine for the nose (husband read it for her)* *Doesn't involve blood samples*	*Expecting test results*
Participant 2, HHI **(Female, 45yrs, Secondary education)**	*Screening the body/ assessing ones health*	*Find out proportion of children who didn't get PCV if they have some of the 13 germs and whether these are appropriate for the current vaccine*	*Wanted to find out if the child has some of the 13 germs*	*feedback within the 4 years*
Participant 3, South Lunzu **(Female, 47yrs, Primary education)**	*wants to find out about diseases or water, don't really know, the government wants to find out the truth about an illness*	*Wanted to do a comparison between people who received the vaccine and those who don't...can't remember the rest...want to know if it's necessary for older people to receive the vaccine*	*The research will help to find out the truth about pneumonia*	*Need for feedback...wants to know how research has benefited the country*

Appendix 15: Publication on Community Advisory Groups

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ORIGINAL ARTICLE

WILEY developing world bioethics

'We are the eyes and ears of researchers and community': understanding the role of community advisory groups in representing researchers and communities in Malawi

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Abstract

Community engagement to protect and empower participating individuals and communities is an ethical requirement in research. There is however limited evidence on effectiveness or relevance of some of the approaches used to improve ethical practice. We conducted a study to understand the rationale, relevance and benefits of community engagement in health research. This paper draws from this wider study and focuses on factors that shaped Community Advisory Group (CAG) members' selection processes and functions in Malawi. A qualitative research design was used; two participatory workshops were conducted with CAG members to understand their roles in research. Workshop findings were triangulated with insights from ethnographic field notes, key informant interviews with stakeholders, focus group discussions with community members and document reviews. Data were coded manually and thematic content analysis was used to identify main issues. Results have shown that democratic selection of CAG members presented challenges in both urban and rural settings. We also noted that CAG members perceived their role as a form of employment which potentially led to ineffective representation of community interests. We conclude that democratic voting is not enough to ensure effective representation of community's interests of ethical relevance. CAG members' abilities to understand research ethics, identify potential harms to community and communicate feedback to researchers is critical to optimise engagement of lay community and avoid tokenistic engagement.

KEYWORDS

Africa, bioethics, community advisory group or community advisory board, community engagement, community representatives, research

1 | BACKGROUND

Community engagement or public/patient involvement (PPI) is increasingly promoted in international research guidelines to protect communities from exploitation and harm. Studies in low income countries have shown that research presents a high risk of exploitation because some people may participate without full understanding of risks and benefits, since they are attracted to monetary incentives or health

care.[1] Engaging communities to advise on conduct of health research is therefore seen as a means of improving ethical research practice.[2] Community engagement is also seen as helping to design research that responds to concerns in a community, improve trust, relevance, success and sustainability of interventions.[3] There is however no widely agreed definition of community engagement and we employed the Council for International Organisations of Medical Sciences definition of community engagement because it offers ethical guidance on how to strengthen representation of communities in study design. We therefore define community engagement as:

> *a process of engaging potential participants and communities in a meaningful participatory process that involves them in an early and sustained manner in the design, development, implementation, design of the informed consent process, monitoring of research and in the dissemination of its results.*[4]

While we concur that community members have capabilities to identify their needs and they should be actively involved in finding solutions to these needs,[5] the degree of participation deserves critical attention. According to Sherry Arnstein, there are degrees of participation ranging from nonparticipation to citizen control.[6] Nonparticipation occurs when communities are involved to be educated; tokenism occurs when they are informed or consulted but they lack power to influence decisions; while citizen control is attained when they are actively involved in planning, designing and have power to influence decisions.[7] This implies that meaningful engagement occurs when all parties effectively participate in discussions to identify solutions. The feasibility of integrating both lay and scientific perspectives in research design however remains a challenge particularly in low literacy settings.

One of the approaches used to involve communities in health research is the use of a Community Advisory Board (CAB) or Community Advisory Group (CAG). Community Advisory Groups were initially introduced in HIV/AIDS research to strengthen the representation of people affected by or living with HIV/AIDS in research planning and implementation.[8] Some donors now require establishment of a CAG, particularly in low resource settings, to provide community oversight on ethical conduct of health research.[9] Roles of CAG include reviewing study protocols and informed consent forms, representing community concerns, advocating for the rights of research participants, consulting with potential research participants to provide advice, identifying research priorities, assisting in development of study materials, study design and implementation.[10]

While engaging a CAG is designed to strengthen community engagement, existing literature demonstrates challenges. Some of the challenges include limited understanding of health research, monetary expectations, dependence on researchers for finances, and lack of authority to influence decisions concerning research.[11] These challenges have led to scepticism about the advisory roles of CAG members and concerns that their involvement is sometimes tokenistic or 'window dressing' to fulfil donor requirements.[12]

In this paper, we report findings from an ethnographic study in Malawi that seeks to understand the purpose, relevance and benefits of community engagement as seen by different stakeholders in research. We start by discussing approaches used to select the CAG members and how these affected their roles. We also discuss contextual factors in urban and rural settings that affected selection and functions of CAG members and community perceptions of the CAG.

Models of CAG vary in terms of both composition and selection processes. In relation to composition, CAG vary in terms of whether they represent the broad community or specific populations.[13] Similarly to the term community engagement, there is no widely

[1]Emanuel EJ, Wendler D, Killen J, Grady C. What Makes Clinical Research in Developing Countries Ethical? The Benchmarks of Ethical Research. Journal of Infectious Diseases. 2004;189(5):930-7; Geissler PW, Kelly A, Imoukhuede B, Pool R. He is now like a brother, I can even give him some blood'- Relational ethics and material exchanges in a malaria vaccine trial community in the Gambia. Social Science & Medicine. 2008;67:696–707; Massawe IS, Lusingu JP, Manongi RN. Community perception on biomedical research: A case study of malariometric survey in Korogwe District, Tanga Region, Tanzania. BMC Public Health. 2014;14(1):1–9; Mfutso-Bengo J, Ndebele P, Jumbe V, Mkunthi M, Masiye F, Molyneux S, et al. Why do individuals agree to enrol in clinical trials? A qualitative study of health research participation in Blantyre, Malawi. Malawi Medical Journal. 2008;20(2):37.

[2]Dickert N, Sugarman J. Ethical Goals of Community Consultation in Research. American Journal of Public Health. 2005;95(7):1123–7.

[3]Mikesell L, Bromley E, Khodyakov D. Ethical Community-Engaged Research: A Literature Review. American Journal of Public Health. 2013;103(12):7–14; Minkler M. Community-based research partnerships: Challenges and opportunities. Journal of Urban Health : Bulletin of the New York Academy of Medicine. 2005;82(Suppl 2):3–12.

[4]Council for International Organisations of Medical Sciences. International Ethical Guidelines for Health-related Research involving Humans, Fourth Edition 2016 [cited 03 April, 2017]. Available from: http://cioms.ch/ethical-guidelines-2016/WEB-CIOMS-EthicalGuidelines.pdf.

[5]Glassman M, Patton R. Capability Through Participatory Democracy: Sen, Freire, and Dewey. Educational Philosophy & Theory. 2014;46(12):1353–65.

[6]Arnstein S. A Ladder of Citizen Participation. JAIP. 1969;35:216–24.

[7]Ibid

[8]Cox LE, Rouff JR, Svendsen KH, Markowitz M, Abrams DI. Community Advisory Boards: Their role in AIDS clinical trials. Health & Social Work. 1998;23(4):290–7.

[9]Boulanger RF, Seidel S, Lessem E, et al. Engaging communities in Tuberculosis research. Lancet. 2013;13:540–5.

[10]Morin SF, Maiorana A, Koester KA, Sheon NM, Richards TA. Community consultation in HIV prevention research: a study of community advisory boards at 6 research sites. Journal of Acquired Immune Deficiency Syndromes. 2003;33(4):513–20; Newman SD, Andrews JO, Magwood GS, Jenkins C, Cox MJ, Williamson DC. Community Advisory Boards in Community-Based Participatory Research: A Synthesis of Best Processes. Preventing Chronic Disease. 2011;8(3):1; Quinn SC. Ethics in public health research: protecting human subjects: the role of community advisory boards. Health Policy and Ethics Forum. 2004;94(6); Strauss RP, Sengupta S, Quinn SC, et al. The Role of Community Advisory Boards: Involving Communities in the Informed Consent Process. American Journal of Public Health. 2001;91(12).

[11]Cox LE et al. *op. cit.* note 8; Morin SF et al. *op. cit.* note 10; Manda-Taylor L. Establishing community advisory boards for clinical trial research in Malawi: engendering ethical conduct in research. Malawi Medical Journal. 2013;25(4):96; Shubis K, Juma O, Sharifu R, Burgess B, Abdulla S. Challenges of establishing a Community Advisory Board (CAB) in a low-income, low-resource setting: Experiences from Bagamoyo, Tanzania. Health Research Policy and Systems. 2009:7; Pratt B, Lwin KM, Zion D, Nosten F, Loff B, Cheah PY. Exploitation and community engagement: Can community advisory boards successfully assume a role minimising exploitation in international research? Developing World Bioethics. 2015;15(1):18–26.

[12]Quinn SC. *op. cit.* note 10.

[13]Morin SF et al. *op. cit.* note 10; Shubis K et al. *op. cit.* note 11; Manda-Taylor L *op. cit.* note 11; Pratt B et al. *op. cit.* note 11; Reddy P, Sifunda S, James S, Naidoo N, Buchanan D. The role of community advisory boards in health research: Divergent views in the South African experience. Sahara J. 2010;7(3):2–8.

agreed definition of a community.[14] As such, the term community can be externally defined to refer to: a group of people residing within a particular geographical location, a group of people with a common characteristic, identity or illness, or simply, a group of people residing within the immediate surroundings of a health facility. The ambiguity of the term 'community' therefore presents challenges on who should legitimately represent community's interests in health research.

Recommendations on composition of CAGs include having a group with equal numbers of representatives of the traditional authority, democratically elected residents and participant representatives;[15] a group of community leaders or a group with equal numbers of representative residents and participant representatives.[16] Selection approaches for CAG members also vary between contexts. A mix of purposive selection, elections and mixed methods approaches have been reported in the literature.[17] One of the recommended approaches to choosing representatives is through democratic elections.[18] Buchanan suggests that CAG members must be selected through democratic elections if they are to have authority to speak on behalf of the community.[19]

While recommendations on both CAG composition and selection relate to ideas of representation, the concept of representation is complex, particularly in governance of health research. The Oxford Dictionary defines representation as: *'speaking or acting on behalf of someone or formal statements made to an authority'*.[20] However, representation or representativeness may also mean possessing characteristics similar to a particular group.[21] While professional certification may authorise an individual to represent scientific interests, it is debatable what should authorise CAG members to represent community interest. The diversity in communities and technical expertise required in health research make the question of whom and how should communities be represented difficult. Few publications have focused on the feasibility of different selection approaches and consequent effects on CAG members' role of representing communities. The dual roles of CAG members in representing community interests to researchers and vice versa, as well as to balance their conflicting interests have also not been adequately covered in the literature. This paper therefore seeks to contribute to these knowledge gaps.

2 | METHODOLOGY

2.1 | Setting

This study was conducted in an urban and a rural district in southern Malawi, where the Malawi Liverpool Wellcome Trust Clinical Research Programme (MLW) is implementing medical research projects. Malawi has a population of 17,215,000, and a majority of people (84%) reside in rural areas.[22] The literacy rate for adults above 15 years old is 75% and literacy rates are lower in rural areas.[23] The country is faced with a huge disease burden and the leading causes of mortality are: HIV/AIDS, malaria, pneumonia, diarrhoea, Tuberculosis (TB) and non-communicable diseases.[24]

MLW was established in 1995 and initially focused on conducting research on malaria. At the time the study was conducted in 2015, MLW had implemented over 50 research projects covering a broad range of research topics including: HIV/AIDS, TB, malaria, non-communicable diseases and vaccines. A Science Communication department was established at MLW in 2008 to lead both programme wide and study specific engagement activities. Some of the public/community engagement activities run by this department include: managing CAGs, running science cafes, a science exhibition project, a weekly radio programme, and regular community sensitization meetings. Two CAGs were set up in 2009 in an urban and rural setting respectively where MLW was implementing research projects. Twenty six members were selected from six townships in the urban district in Blantyre and 48 members were selected from 39 villages in the rural district in Chikwawa. The roles of the CAG were to identify community concerns or potential harms and to feedback these to MLW researchers. A manual was developed by science communication staff which was used to guide selection, operation and training of CAGs. There were, however, no clear guidelines to determine the types of studies needing to engage a CAG. The decision to engage a CAG in a research project was therefore left optional to researchers.

CAG members were volunteers who resided in geographical locations where MLW was implementing research; CAG members from urban areas were selected from geographical locations surrounding health facilities which hosted various research projects. For rural areas, CAG members were selected from geographical locations where a community based intervention was being implemented. CAG members were trained by science communication staff on the following topics: MLW's vision, functions of CAG, clinical research, protection

[14]Macqueen KM et al. What Is Community? An Evidence-Based Definition for Participatory Public Health. 2001; Marsh VM, Kamuya DK, Parker MJ, Molyneux CS. Working with Concepts: The Role of Community in International Collaborative Biomedical Research. 2011; Tindana P, Singh J, Tracy S, et al. Grand Challenges in Global Health: Community Engagement in Research in Developing Countries PLoS Medicine. 2007;4(9).

[15]Buchanan D, Sifunda S, Naidoo N. Assuring Adequate Protections in International Health Research: A Principled Justification and Practical Recommendations for the Role of Community Oversight. Public Health Ethics. 2008;1(3):246–57.

[16]Ibid.

[17]Ntshanga SP, Ngcobo PS, Mabaso MLH. Establishment of a Community Advisory Board (CAB) for tuberculosis control and research in the Inanda, Ntuzuma and KwaMashu (INK) area of KwaZulu-Natal, South Africa. Health Policy. 2009;95(23):211–5; Pinto RM, Spector AY, Valera PA. Exploring group dynamics for integrating scientific and experiential knowledge in Community Advisory Boards for HIV research. AIDS Care. 2011;23(8):1006–13; Reddy P et al. *op. cit.* note 13; Shubis K et al. *op. cit.* note 11.

[18]Brieland D. Community advisory boards and maximum feasible participation. American Journal of Public Health. 1971;61(2):292-6; Buchanan D et al. *op. cit.* note 14.

[19]Buchanan et al. *op. cit.* note 15, p. 7.

[20]Oxford University Press. *Oxford Dictionaries Language Matters*. 2016 [Accessed 24 June 2016]; Available from: ttp://www.oxforddictionaries.com/definition/english/representation.

[21]Brown MB. Science in democracy: expertise, institutions, and representation [electronic book]. Cambridge, MA : MIT Press, c2009.; 2009.

[22]The World Bank. Malawi-The Country at a Glance 2016 [updated 2016; cited 27 June, 2016]; Available from: http://www.worldbank.org/en/country/malawi

[23]National Statistics Office & ICF Macro. Malawi Demographic and Health Survey 2010. Zomba, Malawi: NSO & ICF Macro; 2011.

[24]SanJoaquin MA, Molyneux ME, Benjamin L, et al. Surveillance Programme of IN-patients and Epidemiology (SPINE): Implementation of an Electronic Data Collection Tool within a Large Hospital in Malawi. PLoS Medicine. 2013;10(3); WHO. Malawi: WHO statistical profile. 2015 [updated 2015; cited 27 June, 2016]; Available from: http://www.who.int/gho/countries/mwi.pdf

of research participants, leadership skills and report writing. MLW organized quarterly meetings for CAG members and the science communication team, where CAG members presented their reports and discussed new research projects as well as other ongoing research projects.

2.2 | Data collection

The findings in this paper were part of doctoral research on community engagement in health research. Data collection took place between May 2015 and February 2016 after the CAGs had functioned for six years. Data collection included five different methods: 1) participatory workshop with CAG members, 2) document reviews, 3) participant observation among communities where medical research is conducted, 4) focus group discussions with community members who were not CAG members, and 5) interviews with research staff, CAG members, and community leaders. The study was approved by the University of Malawi, College of Medicine Research Ethics Committee in Malawi and Liverpool School of Tropical Medicine Research Ethics Committee in UK.

2.2.1 | Participatory workshops with CAG members and document reviews

We conducted two participatory workshops with CAG members from each district with an aim of understanding their roles in research. A total of 21 CAG members attended the workshop in the rural setting while a total of 16 CAG members attended the workshop in the urban setting (see Table 1). Workshop participants were purposively selected from a list of CAG members based on gender and geographical location. Both workshops were co-facilitated by the first and third authors. Workshop participants were asked to fill a registration form and a summary of socio demographic details has been provided in Table 1. At the workshop, participants were asked to discuss how they were selected, their roles in research and more specifically who they represent and how they represent them. Responses were noted to understand how participants were selected as CAG members while group discussions were used to understand their roles in health research. Workshop participants also shared experiences of how they executed their responsibilities. Consent was sought from workshop participants to record workshop proceedings and each workshop lasted for about six hours. Following this, we carried out document reviews of past CAG meeting reports in order to understand concerns raised by the CAG members. Preliminary findings were presented to science communication staff for feedback.

TABLE 1 Socio demographic details of workshop participants

	Workshop-rural	Workshop-urban	Total
Gender			
Male	11	10	21
Female	10	6	16
Age			
20-30	7	0	7
31-40	5	6	11
41-50	7	4	11
51-60	2	3	5
61-70	0	3	3
Education			
Primary education	15	4	19
Secondary education	6	5	11
Post secondary	0	7	7
Profession			
Business	0	3	3
Farmer	19	1	20
Community Health Worker	0	5	5

2.2.2 | Focus group discussions, interviews and participant observation

Main themes from the workshops, document reviews and discussions with science communication staff were further explored in subsequent data collection to broaden our understanding of the issues. We conducted eight focus group discussions with men and women from the two sites in order to explore diverse perspectives of how the CAG members functioned in the community. An additional 15 interviews were conducted with key informants to understand certain themes such as selection processes and roles of CAG members in more detail. These key informants were selected based on their involvement in selected research projects and included community leaders, CAG members, research participants and research staff. Topic guides developed from the workshop themes covering issues of selection processes, roles, communication, community concerns and community representation in research were used to facilitate interviews and focus group discussions.

Data from participatory workshops, interviews and FGDs were triangulated with field notes from observations. Participant observation was used to understand both explicit and unarticulated aspects of how the CAG members functioned in the communities. We participated in activities involving researchers, community engagement staff, field workers, CAG members and community members to observe their interactions and to become familiar with the context where they lived.

2.3 | Data analysis

Workshop proceedings were transcribed by the lead author. The transcripts were read and coded manually based on the main issues arising from the discussions. Codes were later grouped into higher level themes of selection, motivation, roles, communication and feedback on research. Thematic analysis was used to compare and present

discussions from the urban and rural CAG in relation to the main themes.

Interviews and focus group discussions were also recorded using a digital recorder and transcribed. A coding framework was developed by the lead author and transcripts were coded in QSR Nvivo 10. Main themes in relation to selection, roles of CAG and representation were used to support findings from the workshops. Findings were triangulated by using multiple data collection methods and crosschecking responses against various informants and the field notes. Results from this study were presented to CAG members for feedback in a separate workshop. We also sought their views on how to select CAG members in the future and empower them to effectively represent community's interests.

3 | RESULTS

3.1 | Challenges with selection of CAG members in urban and rural settings

MLW intended that CAG members would be selected democratically by community members residing in the geographical locations where research projects were being implemented. It was therefore expected that CAG members would reflect socioeconomic characteristics of the community. A democratic selection process required that community leaders would organize community meetings to elect CAG members and individuals would be nominated by fellow community members to participate in an electoral process. Every meeting attendee was asked to vote for their preferred candidate by a show of hands while facing down and the nominee who won the majority of votes would serve as a CAG member.

This election process proved more feasible in rural areas than urban areas. During the workshop, we asked workshop participants how they were selected as CAG members. The responses indicated differences between the urban and rural areas. Most of the workshop participants from rural areas stated that they were elected by fellow community members while a majority of workshop participants from urban areas indicated that they were selected by community leaders or health care workers as shown in the following quote: *'I was chosen by the chief of the whole village to explain to people about research'* (Male, CAG member, urban setting). Workshop participants in both settings believed that they were selected because they were active in other community groups, knowledgeable about health issues or well known in their community.

Implementation of voting system for CAG members was easier in rural than in urban areas. This was because the villages or geographical locations in rural areas were small and communities were more homogeneous. Communities in rural areas were close-knit, shared the same tribe and language, and demonstrated similar socio-economic characteristics. In addition, people in rural areas were often long-term residents in a particular village, familiar with one another and usually available during community meetings because they were mostly farmers. Since a majority of people from rural areas were available during community meetings and they were familiar with one another; this made it possible to nominate and vote for people they trusted to serve as CAG members. However, while community meetings were easy to organize in rural areas, the election process was not always free and fair. For instance, some community members reported that at times some community leaders influenced their followers to vote for people from their clans which clearly raise questions about democratic selection.

In contrast, the settings where research was being implemented in urban areas were larger and more densely populated. A majority of people in urban areas were originally from other parts of the country and had migrated to urban areas in search of employment. In addition, there was also high in and out migration. Communities in urban areas were therefore diverse and comprised of people with different professions and tribes. Community leaders in urban areas reported challenges in inviting people for meetings, and general unwillingness of community members to attend community meetings:

> *Only few people come to attend community meetings; when they hear that researchers are coming for a meeting, most people do not show up, but when they hear that they will receive free stuff or food, they show up* (Male, village head, urban setting).

Participants in the FGD and interviews with community members (who were not part of CAGs but some were participants in research studies) reported challenges in attending community meetings due to other competing activities such as employment, businesses and other social activities:

> *When it comes to issues of research, most people are so reluctant to attend meetings…people complain because they have numerous things to do…some go to work, others do business, they say time is money, for them to come and just listen [to researchers] they feel there is nothing to benefit* (Mother of a research participant, urban setting).

Lack of participation presented challenges in urban areas to select CAG members by democratic process because few people attended community meetings to vote. To fill the gaps in CAG membership, most participants from the urban district stated that they were selected by chiefs or health care workers.

3.2 | CAG members' roles in research

The intended role of CAG members to MLW Science Communication was to identify potential harms and represent community concerns to researchers. Some research staff, however, engaged CAG members to facilitate communication towards the communities and help in implementation of research.

When the workshop participants were asked to discuss their roles in health research, almost all workshop participants stated that they were the bridge between researchers and community members, as illustrated in the following quote: *'I was chosen to be the eyes of health*

care workers, researchers and community members' (Male workshop participant, urban setting). However, while some discussed this as a 'two-way bridge', the focus was primarily on accountability to the researchers. CAG members defined their role as a form of employment or hierarchical duty where the orders came from above rather than below from the community as highlighted in the following quote: *'The one who give us information to relay to others is the one that we listen to, they are like our bosses'* (Male, workshop participant, rural setting).

While the intended role of CAG members was to represent community concerns to MLW; we observed minor differences in the roles of CAG members from urban and rural locations suggesting that the roles of CAG members were shaped in response to the study design, practical demands from research staff and the social context they lived in. The CAG members from urban areas often mentioned communication roles whilst CAG members in rural areas mentioned that they assisted in the implementation of field work activities.

CAG members in the urban district explained that their primary role was in communication: they were informed about new research projects taking place at MLW in order to share this information with other community members and encourage their participation during community meetings. One member indicated that

> *We were told that we are the bridge between researchers and community members to raise awareness of new research in the community and ensure that people are more receptive* (Female workshop participant, urban setting)

On the other hand, CAG members in the rural district indicated that their role was primarily to aide fieldwork: they were often requested by fieldworkers to accompany them to potential research participants' homes and to ensure that research participants comply with research procedures. CAG members therefore perceived that their role was to facilitate implementation of research and ensure that research participants comply with research procedures as shown in the following quotes:

> *...Staff [researchers] usually tell us in advance that they will visit our village and we have to look for people [potential research participants] to work with them and they do that for consecutive days* (Male workshop participant, rural setting).

This discrepancy between role intended by the science communication staff and role understood by CAG members was explained by the science communication staff to be a result of several factors. Science communication staff reported that some CAG members assumed communication and fieldwork roles without being instructed because they hoped to be considered for employment as field workers. This view also surfaced during interviews with CAG members. Some of the CAG members expressed disappointment with researchers for not considering them for fieldwork positions. In addition, science communication staff reported that one of the main concerns raised by CAG members pertained to increasing financial incentives for CAG members rather than reporting back issues from communities. This suggests that membership in CAGs may simply be seen as instruments to address issues of poverty and unemployment; or that CAGs may be set up for instrumental reasons, which in itself is not a problem, but compromises ideals around wider ethical concerns and democratic representation.

3.3 | CAG members' ability to perform their functions in urban and rural settings

We found two major constraints limiting CAG members' roles in performing both the intended role of representing community concerns and the perceived role of communicating study information: community awareness of the CAG, and CAG members' knowledge of the research that they were asked to report on.

We noted that community awareness of a CAG was essential to elicit concerns from community members. Most of the workshop participants in rural settings stated that community members were aware of them and approached them to report problems, seek advice and clarity on issues regarding research. This was seen to help demystify the research when information was obtained from fellow community members and enhanced trust and acceptability of research. CAG members believed that they were able to clear misconceptions which improved acceptability of research as illustrated in the following quote:

> *We are able to clarify misconceptions in the villages because we have relationships with community members. For instance, there was a study in our community and people used to say that when they draw blood, they pay you back in exchange for the blood and we would say no, they are reimbursing you for transport to go to the clinic* (Workshop participant, rural setting)

In urban settings, however, we found that community members who participated in focus group discussions were not aware of the existence of a CAG. This obviously makes it difficult to relay community concerns to the researchers and could have been due to contextual factors discussed earlier, such as large geographical locations, dense population and lack of transparent selection approaches.

The second aspect that affected the CAG's ability to perform their role effectively had to do with communication of scientific procedures. While we noted that in many cases, most CAG members were not able to explain the concept of research accurately through the workshop and reports from previous meetings; we also noted that most CAG members had sometimes difficulties recalling detailed scientific information about the numerous studies that they were involved in. For instance, after presenting the aims of this research in the second workshop, workshop participants were asked to write down the purpose of this research project and what was going to happen. The majority did not give accurate information about the research project which again raises questions about how research would have been communicated to other community

members. These issues show that CAG members' perceived role in communicating research may have been compromised by inappropriate communication or overtly technical research procedures presented in non-lay terminology.

These findings suggest that even though community members selected CAG members who were perceived as health literate, those selected as CAG members were sometimes unable to explain detailed research procedures to others. Overall, the discrepancies in expectations and CAG members' difficulties to perform their role of informing communities about research lead us to question whether CAGs are an appropriate mechanism to represent community interests and ethical concerns.

4 | DISCUSSION

This paper highlights practical experiences of selecting and engaging CAG in a low resource setting. Whilst democratic selection of community representatives is seen to strengthen the roles of CAG to represent community concerns in research,[25] these results have shown that this is problematic across different settings. Despite using democratic selection, we noted that the CAGs did not reflect all relevant socio-economic characteristics of the communities as intended. Since the CAG members were selected based on geographical location; the CAG did not include people who represented interests of other communities affected by the diseases being researched. In addition, rather than being a diverse group representing the demographics of the community, there were no members younger than 20 and a third of the members were community health workers in the urban setting. We also noted that most of the CAG members across both rural and urban areas (21 out of 37) had additional leadership roles in religious and other social groups; they were selected based on their perceived knowledge of health issues; for being known to others; or were preferentially put forward by powerful community members. Other studies have shown that selecting people from positions of authority may lead to choosing individuals whose outlook and interests are not in line with those from the most vulnerable groups.[26] This leads us to question the idea that democratic selection would lead to socio-demographic representation. Clearly, if socio-demographic diversity is sought, extra measures need to be taken to recruit CAG members from these backgrounds.

These findings further suggest that despite selecting CAG members who were seen as 'health literate and influential' by some community members, CAGs were not effective in representing community interests of ethical relevance. Because of the limited evidence to demonstrate how CAG members contributed to reducing harm or exploitation of communities, we argue that use of CAG in facilitating communication between researchers and community can be categorised as tokenistic. The rationale for engaging communities is that the community stands to bear the risks or benefits of research and they have to be protected from harm and exploitation. CAGs provide a mechanism for community consultation on research design in order to minimise potential risks of research to participating communities.[27] Our findings have, however, shown that the CAG members perceived that their main role was to facilitate communication and implementation of fieldwork activities which did not match participatory ideals in the literature. These findings are consistent with other research which showed that CAG or CAB members struggle to perform the expected roles of reducing exploitation during research but see their membership in CAGs as a form of (possible future) employment.[28]

Contrary to the challenges observed in our setting, other studies have reported successful experiences of CAGs providing a mechanism for community consultation.[29] For instance, a study done by Morin in six study sites indicated that CAB members provided constructive feedback to improve the quality of research protocols.[30] Similarly, a study from South Africa reported that CAB members contributed to minimizing exploitation to communities.[31] Despite these few successful examples, challenges to engage communities appear to come down to power dynamics between researchers and CAG members, low science and ethics literacy, and limited access to resources independent from the research projects that they advise on.[32]

Our results suggest that neither democratic nor purposive selection approaches for CAG members led to effective representation of community concerns to reduce harm in research. Despite efforts to engage communities in research design, decision making was mostly done by researchers because of their expertise.[33] We appreciate that researchers are trained and paid to conduct quality research and are accountable to funders but researchers' obligation to conform to scientific procedures and international research ethics may render community representation ineffective if community feedback deviates from internationally acceptable research procedures. Given the findings from this study that CAG members did not provide a mechanism for collaborative partnerships between researchers and community, the question still remains if trying to establish genuine partnerships with communities using CAGs and share equal decision making power is desirable.

[25]Reddy P et al. *op. cit.* note 13.

[26]Brieland D *op. cit* note 18; Kamuya DM, Marsh V, Kombe FK, Geissler PW, Molyneux SC. Engaging Communities to Strengthen Research Ethics in Low-Income Settings: Selection and Perceptions of Members of a Network of Representatives in Coastal Kenya. Developing World Bioethics. 2013;13(1):10–20.

[27]Quinn SC *op cit.* note 10; Strauss RP et al. *op cit.* note 10.

[28]Lwin KM, Cheah PY, Cheah PK, et al. Motivations and perceptions of community advisory boards in the ethics of medical research: The case of the Thai-Myanmar border. BMC Medical Ethics. 2014;15; Morin SF, Morfit S, Maiorana A, et al. Building community partnerships: case studies of Community Advisory Boards at research sites in Peru, Zimbabwe, and Thailand. Clinical Trials. 2008;5(2):147–56 10p; Pratt B et al. *op. cit.* note 11; Reddy P et al., *op. cit.* note 13.

[29]Morin SF et al. *op. cit.* note 10; Pinto RM, Spector AY. *op. cit.* note 17; Reddy P et al. *op. cit.* note 13.

[30]Morin SF, Maiorana A, Koester KA, Sheon NM, Richards TA. Community consultation in HIV prevention research: a study of community advisory boards at 6 research sites. Journal of Acquired Immune Deficiency Syndromes. 2003;33(4):513–20.

[31]Reddy P, Sifunda S, James S, Naidoo N, Buchanan D. The role of community advisory boards in health research: Divergent views in the South African experience. Sahara J. 2010;7(3):2-8.

[32]Pratt B et al. *op. cit.* note 11; Brieland D *op. cit.* note 18.

[33]Cargo M, Delormier T, Levesque L, Horn-Miller K, McComber A, Macaulay AC. Can the democratic ideal of participatory research be achieved? An inside look at an academic indigenous community partnership. Health Education Research. 2008 October 1, 2008;23(5):904–14.

Since existing literature has shown that outcomes of similar models of CAG/CAB may vary across different contexts[34]; several questions remain unanswered on how to optimise the engagement of lay communities and avoid tokenistic engagement across different contexts. In our case, we presented these findings to CAG members and sought their feedback on how to address the challenges. In order to improve representation of community members, CAG members advised that researchers must map social groups in a given context and purposively identify individuals to serve as CAG members. Alternatively, the CAG members suggested using existing self-organised community meetings in urban settings to elect CAG members. We however, acknowledge the limitations of these approaches in that they may not result in a representative group because youths, elderly people and other discriminated groups may be excluded.

Since we have shown that CAG members' role in representing community concerns may be compromised due to their expectations of employment and financial incentives from researchers, we propose that CAGs must be independent. As such, funding for operations of CAG must be unrelated to the projects that they advise on, solicited from independent sources or channelled through independent community based organisations. In order to improve their effectiveness to represent community interests, terms of reference for CAGs should be jointly developed with elected CAG members specifying roles of CAGs and the basis for sharing equal decision-making powers. Such terms of reference should also be made clear to field workers, research staff and community members to improve transparency and accountability. We also concur with other authors that capacity building for CAG members in research ethics, critical thinking and communication is essential for them to function effectively.[35] Most importantly, CAG members should be engaged in determining potential harms to their community and their feedback should be incorporated in research design.

5 | CONCLUSION

We used a qualitative study design to understand functions and effectiveness of CAGs as seen by research participants and community. Our findings indicate that democratic elections of CAG members were not entirely feasible and did not lead to selection of a CAG that reflected diverse community characteristics. Moreover, responses from CAG members failed to indicate how they addressed ethical concerns or discussed potential risks to study participants and communities. Primarily CAG members saw their roles as facilitating implementation of research which is contrary to the ethical mandate in the literature for CAGs.

Despite the challenges, we believe that having CAGs in place can uphold the requirements mandated by ethical guidelines and that communities should be engaged in a meaningful participatory process throughout study design. Further guidance and commitment is however required, on how to achieve this in order to ensure equal decision making power in collaborative partnerships and to avoid tokenistic engagement. We conclude that a non-instrumental set-up of a CAG, shared ideas about their roles in research, and CAG members' understanding of scientific issues, research ethics and ability to communicate feedback aimed to reduce potential harm to communities are critical to meaningful participation.

[34]Shubis K et al. *op. cit.* note 11; Reddy P et al. *op. cit.* note 11; Ntshanga SP et al. *op. cit.* note 17; Lwin KM et al., *op. cit.* note 33.

[35]Morin SF et al., *op. cit.* note 11; Pratt B et al., *op. cit.* note 11.

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CONFLICT OF INTEREST

No conflicts declared.

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Appendix 16: Publication from hospital based case study

PLOS ONE

RESEARCH ARTICLE

Perceptions of Research Bronchoscopy in Malawian Adults with Pulmonary Tuberculosis: A Cross-Sectional Study

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Abstract

Bronchoscopy is an established research tool in Malawi, enabling collection of pulmonary samples for immunological, pharmacological, and microbiological studies. It is, however, an invasive clinical procedure that offers no direct benefit to volunteering participants when used in a research capacity alone, and thus informed consent is essential. This study aimed to explore TB patients' understanding of research bronchoscopy, what would motivate them to participate in research bronchoscopy, and their concerns, in order to inform consenting processes for future clinical studies. We used a qualitative research design. Two focus group discussions were conducted with community members and TB patients to understand their perceptions of bronchoscopy. Transcripts were coded by multiple co-authors and thematic content analysis was used to analyse main findings. We found that Malawian patients with pulmonary TB were willing to participate in a study using research bronchoscopy for health assessment and access to improved healthcare. We identified information of value to potential participants when consenting to that may lessen some of the anxieties expressed by participants. Patient and public involvement is essential to improve informed consent and institutional trust.

Introduction

Fibreoptic bronchoscopy is well-established in routine clinical practice for diagnostic and therapeutic purposes; with bronchoalveolar lavage (BAL) internationally accepted as a research tool [1]. Our research programme in Malawi has used research bronchoscopy to collect pulmonary samples for immunological and microbiological studies, and plans to extend its' use to assessment of intrapulmonary pharmacology, specifically for tuberculosis (TB) drugs.

http://www.wellcome.ac.uk/Funding/Biomedical-science/Funding-schemes/PhD-funding-and-undergraduate-opportunities/WTD037337.htm?utm_campaign=clinical_phd&utm_source=nature&utm_medium=print (ADM). The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Competing Interests: The authors have declared that no competing interests exist.

While bronchoscopy for research purposes has previously been done in healthy adult volunteers and sputum smear-negative pulmonary TB suspects, there is no precedence in Malawian adults with microbiologically-confirmed sputum smear-positive pulmonary TB. Bronchoscopy is an invasive clinical procedure that offers no direct benefit to volunteering participants when used in a research capacity alone. Complications are rare but include chest pain, fever, pneumonia, vocal cord injury, epistaxis, and extremely rarely, death, and thus informed consent is essential [2–4]. Previous work from Malawi suggested that the majority of bronchoscopy-experienced volunteer research participants reported that they valued the research study they were involved in, while new volunteers expected to benefit directly from the research [2]. The main perceived benefits were health assessment and prompt treatment if unwell, rather than remuneration. While most research participants felt they received adequate information before the study, semi-structured interviews identified limited understanding of the procedure in some participants. In order to inform the design of our future studies in TB patients, we sought to involve potential participants in the development of our consenting process and ensure that we addressed their concerns in advance of any procedure.

The Declaration of Helsinki outlines the ethical principles of medical research, and enshrines the need for informed consent, freedom from coercion, and protection of patient safety in research studies [5]. Health literacy, trust, and the quality of the interaction between patient and provider may all positively influence the quality of the consenting process and extent of engagement in research [6]. While written information and signed consent represent the standard, difficulties and controversy may arise in low-income settings where low levels of formal education, limited access to medical services and differing values and interpretation of health and illness make the practical application of these standards challenging [7, 8]. Engaging patients or public in research prior to study implementation is therefore seen to address their concerns, enhance trust, and can improve informed consent, mutual learning, recruitment and retention of research participants [9]. Patient and public involvement (PPI) is increasingly being advocated in health research to prevent harm to participants, improve the relevance of information sheets and the quality of informed consent [10, 11]. Boulanger (2013) however argues that little attention has been given to community engagement or PPI in TB research and this paper contributes to this knowledge gap [12].

We aimed to explore the needs and concerns of prospective research bronchoscopy participants, in order to inform study design, information provision, and consenting processes for our future clinical studies. This descriptive study highlights topics of importance to participants in research bronchoscopy studies, and may inform consenting processes for other invasive procedures in low-income settings.

Materials and Methods

Research team

Focus group discussions (FGDs) were facilitated by two experienced female, Malawian Social Scientists (DN and ML). At the time of data collection, DN was a Social Science PhD candidate and ML was a Social Science Researcher, both based at the Malawi-Liverpool-Wellcome Trust Clinical Research Programme. Both were native Chichewa speakers. The principal investigator (AM) is a British Infectious Diseases Physician who was planning to use bronchoscopy in a study assessing the intrapulmonary pharmacology of TB drugs. He was present at FGDs to answer any study- or bronchoscopy-specific enquiries, but as a non-Chichewa speaker, his role was limited to that of an observer.

Study participants had not met the researchers prior to taking part in the FGDs. Study researchers were not part of normal TB service provision, and participants were advised that

taking part would not affect their current care. Participants were aware that AM was planning a bronchoscopy-based study of TB drugs, and that this work would be used to guide the recruitment and consenting processes in future work.

Study design

This was a cross-sectional study of adult patients with pulmonary TB, and other members of the community in urban Blantyre, Malawi. We used a phenomenological approach to gather information on the perspectives and views of TB patients with regards to research bronchoscopy studies. Two FGDs were organised with the assistance of the TB officers at Queen Elizabeth Central Hospital (QECH), a large district and referral hospital. The first group (FGD1) consisted of mixed community members with some experience of TB—for example, spouses / carers of patients. The second group (FGD2) consisted of TB patients on treatment, but living at home and referring regularly to hospital. This enabled comparison of the perception of research bronchoscopy between healthy lay persons and TB patients. While many of the participants had experience of TB illness and care, none had experience of bronchoscopy. FGDs were chosen to enable the exploration of abstract concepts and social norms in the absence of embodied experience of bronchoscopy in these groups.

The two FGDs occurred in Ndirande, an urban settlement in Blantyre in the catchment area for QECH, in July 2014. This site was chosen as a future recruitment location for research bronchoscopy studies. Participants were included provided they were over 18 years old and could give informed consent. TB patients registered and receiving treatment at Ndirande Health Centre—prospective participants to our future work—were invited to attend a FGD. Twelve participants were recruited into each group, in approximately equal numbers of men and women. Participants were recruited by convenience sampling, reflecting the process of recruitment to the proposed research bronchoscopy study. By interviewing mixed groups, we aimed to capture the dynamic in the TB Registry, where mixed participants registering for TB treatment would be recruited to a bronchoscopy-based study. Three participants in FGD2 failed to attend the FGD. The demographics of the participants are summarised in S1 Table. All of the FGD participants were employed and educated to a minimum of Standard Two (primary school). Twelve participants were educated to secondary level. The FGDs occurred in a community hall.

Participants were provided with an information sheet for the study in Chichewa, the native language of the participants. After written consent to participate, the information sheet explaining the proposed research bronchoscopy TB pharmacology project (S1 File) was read to the participants in Chichewa, and they were given the opportunity to ask questions. Sections requiring further clarification, such as the details of the bronchoscopy procedure and the difference between research and clinical care, were explained further and the relevant sections re-read. The content of the information sheet was refined for FGD2 based on the feedback from the first group. A topic guide with open-ended questions was used to facilitate the FGDs (S2 Table), and included the broad themes of understanding of research, motivation for participation in studies of this nature, concerns, and feedback. These themes were developed through a deductive conceptual framework, drawing on pre-conceptions and previous work on bronchoscopy-based research in Malawi [2]. FGDs were recorded using a digital recorder, transcribed verbatim and translated into English. FGDs took approximately two hours, with field notes taken during the FGDs. Transcripts were checked for quality and accuracy by those who conducted the FGDs

Analysis

The FGD transcripts were coded manually by AM, DN, and WL. We developed an initial coding framework based on a combination of research questions and an inductive approach to

document emergent themes from the data. Emergent themes were triangulated through multiple and independent coding (AM, DN & WL). The coding frameworks were compared, refined and updated through regular meetings. Using thematic content analysis, a matrix of responses from the FGDs was generated in Excel (Microsoft Excel 2013, Microsoft Corporation, Redmond, WA, United States of America). The responses from the two FGDs were compared for similarities and differences across each theme using constant comparison approaches [13]. Direct quotations from research participants cited were chosen explicitly to represent dominant themes emerging from the thematic analysis. We drew on COREQ guidelines when reporting our findings.

Ethical approval

This study was approved by the University of Malawi, College of Medicine Research Ethics Committee (approval number: P.05/14/1575). All participants gave written informed consent (or a witnessed thumb print if illiterate) to take part in the study.

Results

Understanding of health research

In both FGDs, participants had difficulty distinguishing between research and a health intervention. Both groups expressed a motivation to participate in this proposed project as they expected to benefit directly from clinical assessment. For some, this was simply the benefit of being a part of a research study with clinical input beyond that received in standard TB care. For many participants however, they felt that the bronchoscopy would give them immediate information about their "*health status*", and an indication of how well the TB drugs were working in their body. A typical response was:

> *"I can join this research study because I would like them to examine me and find out how I am inside (internally) as I am taking the drug, saying: is the drug functioning well? On the other hand, there is a possibility that they can add more of that drug to me."*
> ***Participant, FGD1***

In FGD2, the interviewers attempted to improve the informed consent process by carefully explaining the difference between research and clinical care, and that participation in health research did not equate to receiving *"special treatment"*. The patient information sheet was adjusted to state that participants would not benefit directly from participation in the study, but that the results may lead to improved treatments for TB in the future. Despite these changes, those in FGD2 still expected immediate benefit from the research in terms of improved therapy or individual feedback on drug effectiveness.

Motivation for participation

Participants were invited to consider their motivation for participating in a research bronchoscopy study in which they did not personally stand to benefit. Motivation was typically framed as altruistic by participants in both FGDs, in that it may benefit future patients with TB. One participant, an older male, gave the analogy:

> ***Participant*: "***We all seem to be those people helping to build a bridge, by assisting to pass over the materials required to construct the bridge, so that every person should what?"*
> ***All*: (*overlap*) "***they should cross properly***"

Participant: *"Therefore we are not forced; it is all up to you to decide for yourself saying: for the bridge to be complete there is need for me to go and cut down trees."*

Participant, FGD1

Some reported they had a responsibility to participate in TB research to further research and improve care.

". . . research is done to find an answer. Therefore, for the answer to be found quickly, there is need for me to be with them on the same side [I need to participate in the research] so that the research should move on well."

Participant, FGD1

Those with TB in FGD2 discussed the burden of TB, and that by participating in research studies such as this they could help fight to eliminate the disease.

Concerns

Fear of exploitation. Participants in FGD1 raised concerns that research may be exploitative, and that safeguarding of participant's safety may be a secondary concern. Typical responses included:

"On the other hand they say: whenever a research is coming up, the government indicates or even signs that it doesn't care for those 200 or 300 people [enrolled in research], even if they die. This is the reason why most people get discouraged saying: aah should I die (laughter), the fears happen to be there."

Participant, FGD1

"People say: whenever there is a research, we feel that maybe the health sector [Ministry of Health] would like to use us to gain knowledge. Most people like to say that: aah I cannot join a research; they would like to learn from our bodies, most people like to put it that way."

Participant, FGD1

"When new research projects are coming in, some people say: they want to learn using our bodies, they are the people chewing a lot of money, but when the research is happening, it is done on us."

Participant, FGD1

This fear of exploitation was not expressed in FGD2 –those with personal experience of TB illness and healthcare delivery.

Fear of potential risks of research bronchoscopy. Having explained the research bronchoscopy patient information sheet to the focus group participants, they were invited to give their opinions on the use of bronchoscopy as a tool to investigate TB drugs. Participants were mainly in favour of the research, though some expressed some apprehensions. Much of the fear emerged from participants having a limited understanding of the bronchoscopy procedure and any potential risks given the information provided. Anxieties stemmed from being unable to visualise the bronchoscope itself, and were assuaged by inclusion of an illustration and explanation of the size of the instrument in FGD2.

In FGD2, a number of participants sought clarification on the 'fluids' taken during the bronchoscopy procedure. It became apparent that the use of BAL, or washing, was not clear, and that participants took this process to be akin to taking blood (by venepuncture). As such, a number of participants discussed the bronchoscope entering *"small veins"* within the lungs. Participants sought clarity on the appearance and texture of the bronchoscope, concerned it

may be the size of a *"water pipe"* or made up of metal. Another participant in FGD1 expressed anxieties that the bronchoscopy procedure may adversely affect the circulation of the blood if they draw a lot of fluid from one's body.

We sought comments on further information of importance to potential participants. Participants requested specific detail about the duration of the intervention, and the expected duration of any side effects. Fever was included as a rare side effect in the patient information sheet (S1 File), but a number of participants in FGD1 focussed on how long this side effect could be expected to last. By including this information, they would have an idea when to be worried about the duration of side effects and seek help. Rather than deterring participants, full disclosure of risks was appreciated. Furthermore, accurate information was important for trust of the study team.

> *"As for me, I feel that in that case, if I feel pain or whatsoever [side effect], the way they have explained it, and they have counselled me that you will feel pain to this extent, if I experience it, I will come back [for a second bronchoscopy]. But if it [the side effect] exceeds the limit [beyond what was initially discussed]: like you said:* ***24 hours*** *of pain and fever for* ***two days****, this means that the research study is different from what you have told us."*
>
> ***Participant, FGD1***

Other information that would be appreciated included how long the cough may last after bronchoscopy, and how long the anaesthesia would be expected to last. Pain and bleeding were rarely mentioned in the discussions, but again, duration and amount were issues that concerned participants.

Views on HIV testing. Routine testing for HIV as a criterion for participant recruitment was raised as a concern by participants in FGD1, and there was a feeling that this should be optional.

> *"As for me, what I feel is that most of us get troubled inside our hearts, saying: AIDS is incurable, therefore people become scared, that it's better to stay without knowing your health (HIV) status. But as for TB we know that this is curable."*
>
> ***Participant, FGD1***

This did not seem to be an issue with the TB group—FGD2 –presumably as HIV testing and counselling is an established part of the TB diagnostic process and reflected their clinical experience. This was echoed by a number of participants, who appreciated the importance of diagnosis, even when asymptomatic, primarily for treatment reasons:

> ***Interviewer:*** *"...Is the person joining this research study supposed to undergo an HIV test?"*
>
> ***All:*** *"Yes"*
>
> ***Interviewer:*** *"Do you feel this is appropriate?"*
>
> ***All:*** *"Yes!"*
>
> ***Interviewer:*** *"Why is that so?"*
>
> ***Participant:*** *"Because he/she will know about her body if he/she has TB...therefore you are in a position to know whether you have TB as well as HIV... and you get treated for both of these"*
>
> ***Participants, FGD2***

Results feedback and compensation

A common concern of participants was that results should be fed back to the community, with some commenting that they do not even know when a study is ended:

"When the research comes to an end, they just leave and go. . . We still think that we are enrolled in the research study not knowing that we are out." (laughter)

Participant, FGD1

As payment for participating, information about the study's results was considered to be a requirement:

". . .because I was one of those people participating in the study [research participant], therefore I should know the answer to the research study [research findings]."

Participant, FGD1

Other than the results of the study, an idea of how many people the study results stand to benefit was requested, and whether any recommendations were made to improve TB treatment by the researchers.

Some participants felt that the clinical assessment itself was a motivation and reward for recruitment into a research bronchoscopy study, and many voiced that any adverse events or intercurrent illnesses occurring within the course of such a study should be treated promptly. Participants in FGDs with TB patients, were aware of other studies providing prompt healthcare outside the study interventions. One participant in FGD2 indicated that they felt that medical care above that available in Malawi may be a suitable recompense for an adverse event, but this opinion was not echoed by the other participants.

"For instance if a person has severe bleeding and not as expected, saying: it did not come out the way you had expected it to come out, you must give her treatment to stop the bleeding. They must take her to big hospitals if they feel that the problem is major, regardless of how much it will cost. . .the researchers must take responsibility if the patient becomes severely ill because they enrolled in the research. . .They should find treatment even if it means flying the patient outside the country."

Participant, FGD2

Compensation requests were modest: reimbursement for transport or a meal allowance were the commonest suggestions. Others suggested that counselling and additional study visits were of benefit enough to them. In FGD1, there were a number of participants who felt that the compensation should reflect the distance travelled to the hospital, and furthermore, that consideration should be given to lost earnings as a result of taking part:

"Because from a women's perspective, if you want us to be in a research study we will have to leave our homes at the time that you have asked us to meet you. Maybe we had plans to go and pick sweet potato leaves [for food], we failed, because we only have limited time. With the money [compensation] given we could pass by the market and use the same money to buy some mustard and charcoal, and cook [a meal]."

Participant, FGD1

Discussion

In this study, we explored perceptions of research bronchoscopy in a population of Malawian adults, in order to inform the design of future clinical studies using bronchoscopy. Findings indicate a general willingness to participate in studies of this nature, primarily for accrual of personal benefits. Participants expected to benefit directly from clinical assessment, and had

difficulty distinguishing between research and routine clinical care. We identified shortcomings in the informed consent process that will inform clinical practice for future research bronchoscopy-based studies. Through the FGDs, we identified information of value to potential research participants that will guide subsequent engagement strategies.

In this group of bronchoscopy-naïve individuals, there was a common difficulty in distinguishing between interventions performed solely for research purposes, and standard clinical care. Many participants expressed a wish to participate in a research bronchoscopy study for assessment of their *"health status"*, and expected to receive immediate feedback on drug efficacy and their response to treatment. This was particularly true in FGD1, where participants expected individualised feedback post-bronchoscopy rather than aggregate data at study close. This confusion has been described as 'therapeutic misconception' in similar research settings—a belief that every aspect of a research project was designed to benefit the individual directly—and raises concerns that participants may have difficulty distinguishing between investigational research and health intervention when making an informed choice [6, 14]. Rather than being a fault of the participant, we would argue that this confusion was a shortcoming of the informed consent process and our explanations to FGD participants.

The model of therapeutic misconception places the blame for the misunderstanding with the study participants, and has been described as particularly problematic in resource-limited settings due to a combination of low levels of literacy, poor education, poor access to healthcare, high disease burden, and indeed the impact of illness, suffering, poverty, and provider roles on decision making [14–16]. A meta-analysis of informed consent comprehension in African settings reported that comprehension of key concepts was poor [15]. Understanding the investigative or experimental nature of research is clearly a key component in collecting true informed consent, but may be more challenging in a resource-limited setting. Firstly, care quality in Malawi is limited by shortages of healthcare personnel and medications in Government facilities [17]. Researchers have an ethical and moral obligation to provide healthcare to benefit participants, and thus the appropriate provision of substantial and quality medical care in research can result in genuine difficulty in distinguishing between healthcare and research [6, 17]. Rather than a misconception, the provision of healthcare to study participants may provide incentive to recruitment, with participants actively choosing to enrol in research as a rational endeavour to access better-resourced care. Secondly, the onus should be on the researcher to properly inform potential participants of the research nature of the study, and to underscore the assertion that there can be no guarantee of therapeutic benefit [18]. While we attempted to emphasise the investigational nature of the research in FGD2, participants still expected to directly benefit from bronchoscopy. This information will be used when planning our engagement strategy and informed consent processes in future work.

By inviting bronchoscopy-naïve individuals to the FGDs, we aimed to capture a group similar to those that would be recruited to a future bronchoscopy-based study, and gather their views of research bronchoscopy in the absence of embodied experience. As such, participants were asked to consider their motivation in an abstract way. Both FGDs framed their motivation for participation as altruistic: that it would benefit future patients with TB, or that taking part would contribute to eliminating TB disease. This is likely to reflect a social desirability bias: a product of the need to impress the group rather than a true individual perspective [19, 20]. When asked later to consider compensation for participation in research, participants stated that clinical assessment was both a motivation and a reward, and that they expected to be treated promptly in the event of adverse events or intercurrent illnesses. Furthermore, they should stand to benefit should the study lead to improved TB treatment. Rather than altruism, participants were motivated by eventual self-benefit, or the belief that they may lose out by non-participation.

Limited data from resource-poor settings exists on the motivation of individuals to participate in non-therapeutic biomedical research. In India, one study reported that healthy individuals were most likely to cite financial reward as their motivation, whereas patients would participate after being invited by their treating physician [21]. Altruism, free medical check-up, curiosity, and personal health benefit were also cited as motivation for recruitment to non-therapeutic trials [21]. Recently, a qualitative study from Blantyre, Malawi, identified that ancillary care, monetary and material incentives, and more thorough medical diagnosis encouraged participation in biomedical research [17]. While improved medical care was cited in this study, monetary and material incentives were mentioned rarely, and when compensation was discussed, the requests of participants were relatively modest. Participants in FGD2 commented that compensation should consider lost earnings due to the time spent participating in research. These costs may not be routinely considered in study design, and risk participants being under-compensated rather than induced for their role in research [22]. Both groups expected feedback of results at study completion as compensation for taking part. While one FGD2 participant stated that they may never know if the study they participated in has reached completion, care should be taken to provide community feedback because this important in encouraging institutional trust and ensuring ethical practice. Such feedback is already occurring at our research programme in Malawi through an existing Science Communication Department, through science cafes and community advisory groups, and researchers should continue to be encouraged to use them. Lack of feedback from research studies is a common complaint, even should those results be distressing [23–27]. This may simply be the provision of study conclusions to participants, but where appropriate, any results of importance to individual participants should be fed back to enable appropriate medical care. This has been highlighted in genetic studies, where data on future health risks may be uncovered, but could equally be applied to incidental findings during bronchoscopy [28, 29]. Ultimately, studies should be reciprocal, and not simply extractive.

Whereas previous work from Malawi interviewed bronchoscopy-experienced individuals [2], we sought to assess the understanding of research bronchoscopy in bronchoscopy-naïve participants after provision of a patient information sheet. Potential participants understandably had difficulty envisioning a bronchoscope, and requested information on its' dimensions, appearance, and texture: information that we included for FGD2. Given that these participants were bronchoscopy-naïve, and asked to imagine the procedure, these misconceptions reflect shortcomings in the information provision by researchers, rather than a lack of participant education, and highlight areas for clarification in future bronchoscopy-based research. The FGD participants in this study were keen that the patient information sheet provided explicit information as to the duration and severity of any side-effects in advance of the study, and the accuracy of this information was important to fostering trust.

There are a number of limitations to this study that merit discussion. Firstly, none of these participants had prior experience of invasive procedures such as bronchoscopy, and were asked to consider their involvement in such research in an abstract manner. By so doing, we hoped to understand the perceptions and concerns of a bronchoscopy-naïve population to better reflect those individuals recruited into future projects. Secondly, the use of the FGD method likely shaped the responses to some questions, particularly around motivation. Participants will try to project a positive impression to the group, and the researchers, and should be taken into account in the interpretation of their comments. Furthermore, by choosing to participate in the FGDs in the first place these participants may already be biased in favour of research. It is difficult to know how individual experiences influenced responses with this method, and future work may consider how these responses translate into embodied experience in practice: how many would actually enrol in a research bronchoscopy study? In later work, we will invite

TB patients undergoing research bronchoscopy to return for semi-structured interviews and focus group discussions to explore their experience-based perceptions of research bronchoscopy and the consenting process used.

Some of the study limitations were that only two FGDs were conducted, and we did not triangulate findings across different sources or methods. The small sample size reflected the availability of registered patients to attend the FGDs, and was felt to be adequate for a descriptive study to inform the design of a clinical study. We interviewed participants who were willing to attend the FGD, and supplemented this by interviewing relatives and carers. Nevertheless, the two FGDs gave diverse perspectives on bronchoscopy research and similar themes appeared in both groups. Three authors (AM, DN and WL) were also involved in the data analysis processes to enhance trustworthiness of our research findings.

In conclusion, we have shown that Malawian patients with pulmonary TB are willing to participate in a study using research bronchoscopy, and would do so for health assessment and access to improved healthcare. Clear, illustrated patient information sheets should help lessen some of the anxieties expressed by potential participants, and engagement with the community before and after the study is essential. This study contributes to Malawi-specific findings to issues around ethics and informed consent for invasive procedures that will be of interest to a wider audience.

Supporting Information

S1 File. Draft Patient Information Sheet.
(DOCX)

S1 Table. Subject Demographics.
(DOCX)

S2 Table. Focus Group Discussion Topic Guide.
(DOCX)

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References

1. Rose AS, Knox KS. Bronchoalveolar lavage as a research tool. Semin Respir Crit Care Med. 2007; 28 (5):561–73. Epub 2007/11/03. doi: 10.1055/s-2007-991528 PMID: 17975783.
2. Mtunthama N, Malamba R, French N, Molyneux ME, Zijlstra EE, Gordon SB. Malawians permit research bronchoscopy due to perceived need for healthcare. Journal of medical ethics. 2008; 34 (4):303–7. doi: 10.1136/jme.2007.020461 PMID: 18375686.
3. Credle WF Jr., Smiddy JF, Elliott RC. Complications of fiberoptic bronchoscopy. The American review of respiratory disease. 1974; 109(1):67–72. PMID: 4809166. doi: 10.1164/arrd.1974.109.1.67
4. Suratt PM, Smiddy JF, Gruber B. Deaths and complications associated with fiberoptic bronchoscopy. Chest. 1976; 69(6):747–51. PMID: 1277893.
5. World Medical Association. WMA Declaration of Helsinki—Ethical Principles for Medical Research Involving Human Subjects 2013 [cited 2014 28th April]. Available from: http://www.wma.net/en/30publications/10policies/b3/.
6. Molyneux CS, Peshu N, Marsh K. Trust and informed consent: insights from community members on the Kenyan coast. Social science & medicine. 2005; 61(7):1463–73. doi: 10.1016/j.socscimed.2004.11.073 PMID: 16005781.
7. Molyneux CS, Wassenaar DR, Peshu N, Marsh K. 'Even if they ask you to stand by a tree all day, you will have to do it (laughter). . .!': community voices on the notion and practice of informed consent for biomedical research in developing countries. Social science & medicine. 2005; 61(2):443–54. doi: 10.1016/j.socscimed.2004.12.003 PMID: 15893058.
8. Molyneux CS, Peshu N, Marsh K. Understanding of informed consent in a low-income setting: three case studies from the Kenyan Coast. Social science & medicine. 2004; 59(12):2547–59. doi: 10.1016/j.socscimed.2004.03.037 PMID: 15474208.
9. Mikesell L, Bromley E, Khodyakov D. Ethical community-engaged research: a literature review. American journal of public health. 2013; 103(12):e7–e14. Epub 2013/10/19. doi: 10.2105/ajph.2013.301605 PMID: 24134352; PubMed Central PMCID: PMCPmc3828990.
10. Dudley L, Gamble C, Preston J, Buck D, Hanley B, Williamson P, et al. What Difference Does Patient and Public Involvement Make and What Are Its Pathways to Impact? Qualitative Study of Patients and Researchers from a Cohort of Randomised Clinical Trials. PloS one. 2015; 10(6):e0128817. Epub 2015/06/09. doi: 10.1371/journal.pone.0128817 PMID: 26053063; PubMed Central PMCID: PMCPMC4459695.
11. Ives J, Damery S, Redwod S. PPI, paradoxes and Plato: who's sailing the ship? Journal of medical ethics. 2013; 39(3):181–5. Epub 2012/01/24. doi: 10.1136/medethics-2011-100150 PMID: 22267385.
12. Boulanger RF, Seidel S, Lessem E, Pyne-Mercier L, Williams SD, Mingote LR, et al. Engaging communities in tuberculosis research. The Lancet infectious diseases. 2013; 13(6):540–5. Epub 2013/03/28. doi: 10.1016/s1473-3099(13)70042-2 PMID: 23531390.
13. Corbin J, Strauss A. Grounded theory research: Procedures, canons, and evaluative criteria. Qual Sociol. 1990; 13(1):3–21. doi: 10.1007/BF00988593
14. Appelbaum PS, Roth LH, Lidz C. The therapeutic misconception: informed consent in psychiatric research. International journal of law and psychiatry. 1982; 5(3–4):319–29. Epub 1982/01/01. PMID: 6135666.
15. Afolabi MO, Okebe JU, McGrath N, Larson HJ, Bojang K, Chandramohan D. Informed consent comprehension in African research settings. Tropical medicine & international health: TM & IH. 2014; 19 (6):625–42. Epub 2014/03/19. doi: 10.1111/tmi.12288 PMID: 24636078.
16. Preziosi MP, Yam A, Ndiaye M, Simaga A, Simondon F, Wassilak SG. Practical experiences in obtaining informed consent for a vaccine trial in rural Africa. The New England journal of medicine. 1997; 336 (5):370–3. Epub 1997/01/30. doi: 10.1056/nejm199701303360511 PMID: 9011793.
17. Mfutso-Bengo J, Manda-Taylor L, Masiye F. Motivational factors for participation in biomedical research: evidence from a qualitative study of biomedical research participation in Blantyre district, Malawi. Journal of empirical research on human research ethics: JERHRE. 2015; 10(1):59–64. Epub 2015/03/06. doi: 10.1177/1556264614559888 PMID: 25742667.

18. McGraw MJ, Shearn SP. Principles of Good Clinical Practice: Pharmaceutical Press; 2010.
19. Nederhof AJ. Methods of coping with social desirability bias: A review. European Journal of Social Psychology. 1985; 15(3):263–80. doi: 10.1002/ejsp.2420150303
20. Podsakoff PM, MacKenzie SB, Lee JY, Podsakoff NP. Common method biases in behavioral research: a critical review of the literature and recommended remedies. The Journal of applied psychology. 2003; 88(5):879–903. Epub 2003/10/01. doi: 10.1037/0021-9010.88.5.879 PMID: 14516251.
21. Doshi MS, Kulkarni SP, Ghia CJ, Gogtay NJ, Thatte UM. Evaluation of factors that motivate participants to consent for non-therapeutic trials in India. Journal of medical ethics. 2013; 39(6):391–6. Epub 2013/03/12. doi: 10.1136/medethics-2012-100755 PMID: 23475804.
22. Molyneux S, Mulupi S, Mbaabu L, Marsh V. Benefits and payments for research participants: experiences and views from a research centre on the Kenyan coast. BMC medical ethics. 2012; 13:13. doi: 10.1186/1472-6939-13-13 PMID: 22726531; PubMed Central PMCID: PMC3407030.
23. Fernandez CV, Kodish E, Weijer C. Informing study participants of research results: an ethical imperative. Irb. 2003; 25(3):12–9. Epub 2003/10/23. PMID: 14569989.
24. Partridge AH, Winer EP. Informing clinical trial participants about study results. JAMA: the journal of the American Medical Association. 2002; 288(3):363–5. Epub 2002/07/16. PMID: 12117402.
25. Partridge AH, Burstein HJ, Gelman RS, Marcom PK, Winer EP. Do patients participating in clinical trials want to know study results? Journal of the National Cancer Institute. 2003; 95(6):491–2. Epub 2003/03/20. PMID: 12644548.
26. Snowdon C, Garcia J, Elbourne D. Reactions of participants to the results of a randomised controlled trial: exploratory study. Bmj. 1998; 317(7150):21–6. Epub 1998/07/04. PMID: 9651262; PubMed Central PMCID: PMCPmc28597.
27. Mfutso-Bengo J, Ndebele P, Masiye F. Disseminating research results to research participants and their communities. Malawi medical journal: the journal of Medical Association of Malawi. 2008; 20 (2):64–6. Epub 2009/06/23. PMID: 19537435; PubMed Central PMCID: PMCPmc3345668.
28. Thorogood A, Joly Y, Knoppers BM, Nilsson T, Metrakos P, Lazaris A, et al. An implementation framework for the feedback of individual research results and incidental findings in research. BMC medical ethics. 2014; 15:88. Epub 2014/12/30. doi: 10.1186/1472-6939-15-88 PMID: 25539799; PubMed Central PMCID: PMCPmc4391472.
29. Ravitsky V, Wilfond BS. Disclosing individual genetic results to research participants. The American journal of bioethics: AJOB. 2006; 6(6):8–17. Epub 2006/11/07. doi: 10.1080/15265160600934772 PMID: 17085395.